Deanship of Graduate Studies

AL-Quds University

Quality of Life of Palestinian Cancer Patients in the Absence of Palliative Care Service

Mohamad Hussein Hammad Khleif

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Quality of Life of Palestinian Cancer Patients in the Absence of Palliative Care Service

Prepared By:

Mohamad Hussein Hammad Khleif

B.Sc. Nursing, Bethlehem University, Palestine

Supervisor: Dr. Asma Mohamad Imam

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Prepared by: Mohamad Hussein Hammad Khleif

Registration No.: 21010032

Supervisor: Dr. Asma Imam

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The names and signatures of the examining committee members are as follows:

Head of Committee: Dr. Asma Imam	signature: …….
Internal examiner: Dr. Motasem Hamdan	signature: …….
External examiner: Dr. Amal Bandak	signature: …….

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Dedication

This thesis is dedicated to my wife and children, without their patience, understanding, and support nothing would be done.

Mohamad Khleif

Declaration:

I Certify that this thesis submitted for the degree of Master, is the result of my own research, except where otherwise acknowledged, and that this study (or any part of the same) has not been submitted for a higher degree to any other university or institution.

Signed ……..

Mohamad Hussein Hammad Khleif

Date: 13/1/2013

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Abstract

Background overall Quality of Life (QoL) is fundamental for both well and ill people. For the cancer patients it is a vital issue in the presence of this devastating condition that depletes all the resources on both the individual and community level. This study looked into the cancer patients QoL at the most difficult times of their lives. Cancer is the second leading cause of death in Palestine; 12.4% of all deaths (MOH, 2012). Most of the cases are diagnosed in late stage (Husseini et al, 2009), and very low levels of pain control and palliative care are available (AL-Sadeel Society website, 2012).

Methods The aim of this study is to assess QoL domains scores and symptoms experience within the Palestinian culture. The study was carried out in the only three main settings available for treatment of cancer in the West Bank of Palestine.

In-depth interviews with 10 cancer patients were done to reveal the uniqueness and any special concerns for Palestinian patients. And a cross sectional design studied 323 patients to reveal associated factors with QoL. The data collection tools were structured in-depth-interview questions and the QoL assessment tool of the European Organization for Research and Treatment of Cancer (EORTC QLQ C-30) to which socio demographic data were added.

Findings Both qualitative and quantitative parts of this research were in harmony in representing the poor health related QoL (41.8%) of the cancer patients. The predictors of poor QoL were advanced stage of cancer (β= -0.3, $p<0.001$), poor economical condition (β= 0.19, p=0.001), low educational level (β= 0.12, p=0.04), and long duration of treatment (β= -0.11, p=0.04). As well, the generated qualitative themes supported these results; the main expressed needs of the cancer patients were financial aid, pain management, fully equipped healthcare facilities in their vicinity, availability of medications and qualified staff, eradication of stigmatization, communication and psychosocial support, health education, home nursing care, and palliative care.

QoL functions were low and below half of the full function in most cases; physical (48.5%), role (48.8%), emotional (46%), cognitive (60.5%), and social (50%). Moreover, severe symptoms were experienced by cancer patients; fatigue (66.6%), pain (63%),

insomnia (56.4%), appetite loss (45.3%), and financial difficulties (64.6%). These results were lower than other studies in the region, denoting difficult conditions of Palestinian patients with cancer.

Conclusion Palestinian cancer patients are suffering from quite difficult conditions. These can be divided to two main streams; socio-economic factors of the patients, and inability of the healthcare system to early detect, diagnose, treat, and provide professional support, especially to advanced stages cancer patients.

So, and for better QoL, there is desperate need for integrating palliative care services into the health care system in Palestine as quality improvement, cost-effective and economically efficient measure, and develops social welfare system. As well as, there is a need for early detection, and awareness and education for cancer patients and health care providers.

جودة حياة مرضى السّرطان الفلسطينيّين في ظل غياب الرّعاية التلطيفيّة

اعداد: محمد حسين خليف

اشراف: د. أسمى الامام

ملخص:

الخلفية: ان نوعية و جودة الحياة هي شيء اساسي للأصحاء و المرضى على حد السواء، و بالنسبة لمرضى السرطان الذين يعيشون تحت وطأة هذا المرض الرهيب الذي يستنزف كل الموارد على المستويين الشخصي و المجتمعي فهذه مسألة حيوية جدا.

ان هذه الدراسة تبحث في جودة حياة مرض السرطان خلال احلك ظروفهم المعيشية. فالسرطان هو ثاني مسببات الوفاة في فلسطين حيث يشكل 12.4% من مجموع الوفيات (MOH, 2012)، و معظم حالاته تشخص في المراحل المتأخرة للمرض (Husseini et al, 2009)، بالأضافة الى محدودية التحكم بالألم و عدم توفر خدمات الرعاية التلطيفية (مؤسسة السّديل، 2012).

المنهجية: تهدف هذه الدراسة الى تقييم مقاييس مجالات نوعية و جودة الحياة و الأعراض المصاحبة للسرطان ضمفي فلسطين. حيث أجريت الدراسة في المراكز الثلاث الرئيسية لعلاج السرطان في الضفة الغربية، و بحثت في العلاقة ما بين العوامل الأجتماعية و الديمغرافية و الأقتصادية المصاحبة و مقاييس مجالات نوعية و جودة الحياة و الأعراض المصاحبة للسرطان.

اعتمدت المنهجية على عمل مقابلات معمّقة مع عشرة مرضى سرطان لأستقصاء اي تميّز أو اهتمامات خاصة للمرضى في فلسطين، كما اعتمدت على عمل دراسة مسحية مقطعية لِ 323 مريضاً لأستقصاء العوامل المرتبطة بنوعية حياتهم. حيث تم جمع المعلومات بواسطة مجموعة أسئلة ممنهجة في المقابلات المعمّقة و أداة فحص نوعية الحياة للمنظمة الأوروبية للبحث و المعالجة من السرطان (EORTC QLQ C-30).

النتائج: كانت نتائج البحث الكمّي و النوعي متوافقة في ابراز مدى تدنّي نوعية و جودة الحياة الصحية لمرضى السرطان (41.8%)، حيث كانت المتنبّئات الكمّية لنوعية الحياة التي أثرت بشكل سيّئ هي المرحلة المتقدمة للسرطان ($\beta= -0.3, p<0.001$) و الوضع الأقتصادي المتدنّي ($\beta=$ $0.19, p=0.001$) و المستوى التعليمي المتدنّي ($\beta= 0.12, p=0.04$) و المدّة الطويلة للعلاج ($\beta=$ -

كما جاءت مقاييس الوظائف الحياتية متدنية، اقل من النصف في معظم الأحيان، حيث سجلت الوظائف الجسدية (48.8%) و الدور (48.8%) و العاطفة (46%) و الأدراك (60.5%) و الوظائف الأجتماعية (50%). بالأضافة الى شدّة وجود الأعراض لدى مرض السرطان، حيث سجل مقياس التعب (66.6%) و الألم (63%) و الأرق (56.4%) و فقدان الشهية (45.3%) و الصعوبات المالية (64.6%). كانت هذه النتائج أسوأ من مثيلاتها في المنطقة.

الخاتمة: يتبيّن لنا أنّ مرضى السرطان الفلسطينيين يعانون من مشكلة كبيرة تماماً تتمثّل في محورين رئيسيين هما: العوامل الأجتماعية الأقتصادية لحياة المرضى، و قدرة نظام الرعاية الصحية على الكشف المبكر، و التشخيص، و المعالجة، و توفير الدعم المهنيّ خاصّةً لمرضى السرطان في المراحل المتقدّمة الذين يشكلون 71.4% من مجموع العيّنة.

هنالك حاجة ماسّة الى أدراج خدمات الرعاية التلطيفية الى نظام الرعاية الصحية في فلسطين كأداة ضبط جودةٍ فعّالة أقتصادياً، و موفرةٍ مادياً، و تطوير نظام ضمان اجتماعي، و أيضاً الحاجة الى الكشف المبكر و التوعية و التثقيف لكلٍ من مرضى السرطان و مزودي الرعاية الصحية.

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List of Abbreviations

PC: Palliative Care.

QoL: Quality of Life.

HRQoL: Health Related Quality of Life.

GQoL: global quality of life

PF: physical function

SF: social function

EF: emotional function

CF: cognitive function

RF: role function

FI: financial difficulties

PA: pain

FA: fatigue

DY: dyspnea

CO: constipation

DI: diarrhea

SL: insomnia

AP: loss of appetite

ANOVA: analysis of variance

MOH: Palestinian Ministry of Health

WHO: World Health Organization

MOSA: Ministry of social Affairs

GHS: Governmental Health Services

UNRWA: United Nations Relief and Work Agency

NGO's: Non Governmental Organizations

Chapter One

Introduction

1.1 Background

Quality of life (QoL) is the up to date attracting issue in the world nowadays. The term quality of life is used to evaluate the general well-being of individuals and societies. The term is used in a wide range of contexts, including the fields of healthcare. Quality of life is a wide term that can include multi diverse aspects from wealth, employment and built environment, to physical and mental health, education, recreation and leisure time, and social belonging (Wikipedia, 2011). Quality of life for the cancer patients is a vital issue in the presence of this devastating condition that depletes all the resources on both the individual and community level.

Cancer is one of the first leading causes of death globally, according to WHO it caused 7.6 million deaths in 2008, approximately 70% of cancer deaths occur in low- and middle-income countries (WHO, 2012). Cancer is the second leading cause of death in Palestine, accounting for 12.4% of all deaths (MOH, 2012). According to the Palestinian health information center (PHIC) report (MOH, 2012), the reported new cases of cancer in Palestine were 1,498 in the West Bank, with an incidence rate of 64.2 per 100,000 populations, where the cases of mortality from cancer were 897 persons. National statistics showed that most of the cancer cases are diagnosed at the end stage of the disease (Husseini, et al, 2009); this late diagnosis makes it difficult to treat and control symptoms and results in low survival rates and poor QoL of the cancer patients.

According to WHO 30% of cancer deaths can be prevented by implementation of evidence-based strategies for cancer prevention, early detection and management (WHO, 2012). Furthermore, it has been stated in the literature that at least 100 million people would have improved quality of life (QoL) if today's knowledge of palliative care was accessible to everyone of the public (Stjernsward et al, 2007 a).

Moreover, QoL assessment is a vital instrumental tool to adopt, especially at the primary steps, in developing data bases for future use in formulation of country wide programs to support the efforts for better QoL. Guner et al (2006) cited in their study that QoL assessment considered the most important indicators of the outcome of medical service; provides understanding of nature of disease and experiences of patient, and works as index of efficiency for treatment. There is need for QoL assessment in different places, as it was cited that there is differences between cultural groups in their QoL aspects (Alawadi and Ohaeri, 2009).

Palliative care for those patients is the advanced and most up to date choice that should be provided for them. To our best knowledge, palliative care service is not yet integrated within the Palestinian health care system. So, this study will consider the QoL of the cancer patients in Palestine in the absence of palliative care services that are supposed to provide them with comfort and better QoL.

1.2 Study Problem

It is evident, after searching the literature, that there is no comprehensive assessment of the QoL of Palestinian cancer patients. Despite the fact that some regional studies done in the neighboring Arab countries with their different contexts and circumstances, Palestine has its own special entity and cultural considerations, due to its unique situation under the Israeli occupation with its strict regulations and control over all aspects of life of the Palestinians. So, the researcher went toward studying the QoL of cancer patients in the Palestinian hospitals and how it has been affected by the level of pain and other symptoms management that is provided to them. In addition to that is the fact that, till the time of this study, palliative care service is not yet integrated within the national health care services.

It has been stated in the literature that at least 100 million people would have improved QoL if today's knowledge of palliative care was accessible to everyone of the public. This can be best achieved through taking up a Public Health Strategy approach for translating new knowledge and skills into evidence-based, cost-effective interventions that can reach everyone in the population (Stjernsward et al, 2007 a). This strategy should be included within the national health policy as Stjernsward et al (2007 b) stated. They add that this will facilitate the implementation of palliative care programs in the community and aim for providing care for all people in need of that, and ensures equitable access to affordable medications and therapies (Stjernsward et al, 2007 b).

1.3 Study justification

The quality of life (QoL) is the issue of today's interest; especially the health-related QoL which increased since the 1990s. This is increasing not only because life span of patients is increasing, but also as people are more aware and interested in the quality of life they are living (Guner et al, 2006). Theofilou (2011) discussed the issue of under estimating the need, by many recent policies, for using health related quality of life (HRQoL) measurement as a supplement of the traditional public health's measures of morbidity and mortality. It has been considered a measure of outcome of health care and took the attention of clinicians, researchers, economists and managers (Schwartz and Sprangers, 2002;

Theofilou, 2011). Even though, healthy people 2010 and the Center for Disease Control and Prevention identified it as central goal for public health and an important health outcome (CDC, 2012).

QoL research is either led by researchers looking for medical outcomes focusing on HRQoL, or by medical sociologists with the intention to study economic and social determinants (Schwartz and Sprangers, 2002). So, we are going to study the QoL of our Palestinian cancer patients and measure the effects of the surrounding factors on that life.

Cancer is the second leading cause of death in Palestine, accounting for 12.4% of all deaths (MOH, 2012). Moreover, national statistics showed that most of the cancer cases are diagnosed at the end stage of the disease (Husseini, et al, 2009); this late diagnosis makes it difficult to treat and control symptoms and results in low survival rates of the cancer patients. According to the Palestinian health information center (PHIC) report (MOH, 2012), the reported new cases of cancer in Palestine were 1,498 in the West Bank, with an incidence rate of 64.2 per 100,000 populations, where the cases of mortality from cancer were 897 persons. This also confirms that those newly diagnosed cases of cancer are at an advanced stage and terminally ill, and in need for palliative care service.

Moreover, very low level of pain control and palliative care, low level of staff training, and also low number and level of health facilities that care for cancer patients in Palestine (only three main centers in West Bank) are available. This is based on a need assessment survey in the West Bank of Palestine that was done by a local non-governmental organization for palliative care (AL-Sadeel Society, 2012). Unfortunately, there is scarcity of studies of QoL of cancer patients (Alawadi and Ohaeri, 2009); only one small-scale study was done in 2010 to measure the Quality of Life (QoL) of 70 Palestinian cancer patients in two of the three available centers (Thweib, 2011). Results found that the QoL of Palestinian cancer patients is low in all QoL domains. More intense symptoms were found when compared with regional countries. Thweib's study stressed the importance of palliative care service for Palestinian cancer patients. But on the other hand, it did not focus on all cancer patients in Palestine. The sample size of the study was not representative to generalize study findings.

While pain is considered one of the most important symptoms when talking about cancer; it is also considered one of the main factors that have an apparent effect on the QoL of patients with cancer. Thienthong et al (2006) found a high correlation between the average change of pain intensity and QoL scores; a change of scores of pain of at least 3 points out of 10 had a significant statistical and clinical effect on the QoL of 520 cancer patients. The conclusion of this study suggests the high importance of pain management for better QoL of cancer patients. It provided deeper look into the way those patients see and deal with their disease within their social context.

This study provides information regarding patients' perceived satisfaction with their global health status and their evaluation of their QoL, and adds to the baseline data of the QoL of cancer patients in Palestine. It is further expected that this study will improve national understanding of the need of integrating palliative care and symptom management service within the health care system policies and plans, and encourage stakeholders in Palestine to pay attention to this issue; the thing that might result in decreased patients' and families suffering. In other words, this might positively affects the national concept and methodology of dealing with ill cancer patients, and aligns with the universally approved and accepted concepts of palliative care for cancer patients.

This study feasibility was clear as it was based on the researcher surveying and interviewing of the candidates of the three available settings for cancer care in Palestine. This was followed by the necessary data analysis and processing.

1.4 Research Objectives, Hypothesis and Questions

Purpose of the study

The purpose of this triangulated study (qualitative, quantitative) is to assess the QoL domains scores within the unique Palestinian culture. This will be done in the three settings available for treatment of cancer in the West Bank of Palestine.

Objectives

The objectives of this study were:

Qualitative part:

The objective of using this method is to have an in-depth understanding of any unique or specific factors (cultural, social, ideological or political) that are related to the quality of life of the cancer patients in Palestine, especially, in the absence of supportive palliative care services from the national health care system.

Quantitative part:

1. Assess the GQoL of cancer patients in the West Bank.
2. Assess the QoL domains (functions and symptoms) scores of cancer patients.
3. Assess the relationship between socio-demographic factors and global QoL and domains (functions, and symptoms).
4. Identify determinants (predictors) of GQoL.

Hypothesis

1. H0: There is no significant relationship (at $P<0.05$) between GQoL of cancer patients and the independent variables (gender, age, education, place of residence, income, marital status, living condition, and house ownership, place of treatment of treatment, department, stage, duration of treatment, and region).

2. H0: There is no significant relationship between functions and symptoms of cancer patients with the independent variables (gender, age, education, place of residence, income, marital status, living condition, and house ownership, place of treatment of treatment, department, stage, duration of treatment, and region).

Research Questions

1. What are the factors that affect the QoL of the Palestinian cancer patients?
2. Is there statistically significant relationship between QoL of Palestinian cancer patients and their sociodemographic characteristics?
3. What are the needs of the Palestinian cancer patients?

1.5 Potential difficulties and limitations:

- Accessibility to the three settings and difficulty to reach them under the current imposed restrictions by the Israeli occupation of Palestine. Alternative approaches were used when needed such as filling the questionnaires by patients themselves with the help of their caregivers in case patient was illiterate.

- Difficulty in collecting the data and completing the questionnaire tools assessments, when some participants were in exacerbation stage and not able to respond adequately; due to effects of medication and side effects. In this case, the researcher returned later to assess them or selected randomly another cancer patient.

- Scarcity of literature and research studies related to cancer in Palestine, and unavailability of accurate cancer registry.

Chapter Two

Literature Review

2.1 Introduction

This chapter presents an overview about cancer, burden of cancer, the most common four types of cancer, cancer brief treatment modalities, and stages of cancer. Then, some main figures and statistics regarding cancer in Palestine are presented.

Moreover, the theoretical background includes definitions and aspects of quality of life, palliative care, pain, and some of the quality of life domains are presented according to main international categorizations and definitions.

In addition, previous studies that are related to palliative care as a way to better QoL, the factors that influence QoL; including pain and fatigue, demographic factors, and clinical factors, were discussed.

The literature related to the study assessment tool including its validity and reliability and its effectiveness were presented.

At the end, the economic perspective and public health view of palliative care were discussed. This is a validating part of the need and efficiency of adopting a monitoring system of the QoL of cancer patients, and providing a cost-effective and valid scope of service, that is through palliative care integration into the health care system as a whole. Table (2.1) summarizes some studies that conducted in the contexts of QoL of cancer patients.

2.2 Cancer Overview

Cancer is defined by the WHO as

> "A generic term for a large group of diseases that can affect any part of the body", and it is "the rapid creation of abnormal cells that grow beyond their usual boundaries, and which can then invade adjoining parts of the body and spread to other organs. This process is referred to as metastasis, and is the major cause of death from cancer" (WHO, 2012).

Tobacco use, alcohol use, unhealthy diet and physical inactivity are the main cancer risk factors worldwide (WHO, 2012).

2.2.1. Burden of cancer:

Cancer is one of the first leading causes of death globally, according to WHO it accounts for 7.6 million deaths in 2008, approximately 70% of cancer deaths occur in low- and middle-income countries, and 30% of cancer deaths can be prevented by implementation of evidence-based strategies for cancer prevention, early detection and management (WHO, 2012).

2.2.2. Types of cancer:

The following are the first four types of cancer in Palestine:

Breast cancer: is "Cancer that forms in tissues of the breast, usually the lobules (glands that make milk). It occurs in both men and women, although male breast cancer is rare" (NCI, 2012). The incidence rate of breast cancer in Palestine was 7.6 per 100,000 (MOH, 2011).

Colon cancer: is “Cancer that forms in the tissues of the colon. Most colon cancers are adenocarcinomas (cancers that begin in cells that make and release mucus and other fluids)” (NCI, 2012). The incidence rate of colon cancer in Palestine was 6.2 per 100,000 (MOH, 2011).

Stomach cancer: is “cancer arising from any part of the stomach. Stomach cancer causes about 800,000 deaths worldwide per year” (Wikipedia, 2012). The incidence rate of stomach cancer in Palestine was 5.8 per 100,000 (MOH, 2011).

Lung cancer: is “a disease characterized by uncontrolled cell growth in tissues of the lung. This growth can spread beyond the lung in a process called metastasis into nearby tissue and, eventually, into other parts of the body. Most cancers that start in lung, known as primary lung cancers, are carcinomas that derive from epithelial cells” (Wikipedia, 2012). The incidence rate of lung cancer in Palestine was 3.6 per 100,000 (MOH, 2011).

2.2.3. Treatment Modalities:

Cancer treatment requires a careful selection of one or more intervention, such as surgery, radiotherapy, and chemotherapy. The goal is to cure the disease or considerably prolong life while improving the patient's quality of life. Cancer diagnosis and treatment is complemented by psychological support. Some of the most common cancer types, such as breast cancer, cervical cancer, oral cancer and colorectal cancer have higher cure rates when detected early and treated according to best practices (WHO, 2012).

Chemotherapy: is “Chemotherapy is the treatment of cancer with an antineoplastic drug or with a combination of such drugs into a standardized treatment regimen” (Wikipedia, 2012). It is “Treatment with drugs that kill cancer cells” (NCI, 2012).

Radiotherapy: is “The use of high-energy radiation from x-rays, gamma rays, neutrons, protons, and other sources to kill cancer cells and shrink tumors. Radiation may come from a machine outside the body, or it may come from radioactive material placed in the body near cancer cells. Systemic radiotherapy uses a radioactive substance, such as a radiolabeled monoclonal antibody, that travels in the blood to tissues throughout the body. Also called irradiation and radiation therapy” (NCI, 2012).

Surgery: is “A procedure to remove or repair a part of the body or to find out whether disease is present; an operation to remove tissue or part or all of an organ. For example, mastectomy is Surgery to remove part or all of the breast. There are different types of mastectomy that differ in the amount of tissue and lymph nodes removed” (NCI, 2012).

2.2.4. Stages of cancer:

Staging system: is “A system that is used to describe the extent of cancer in the body. Staging is usually based on the size of the tumor and whether the cancer has spread from where it started to nearby areas, lymph nodes, or other parts of the body” (NCI, 2012).

The roman numbers I to IV usually used for staging cancer, with IV having more progression.

Stage I: cancers are localized to one part of the body.

Stage II: cancers are locally advanced.

Stage III: cancers are also locally advanced. The specific criteria for Stages II and III therefore differ according to diagnosis.

Stage IV: cancers have often metastasized, or spread to other organs or throughout the body.

(Wikipedia, 2012).

2.2.5. Cancer in Palestine:

Cancer is the second leading cause of death in Palestine, accounting for 12.4% of all deaths. 1,498 new cancer cases were reported in West Bank in 2011, 54.3% of those cases were females. The cancer incidence rate was (64.2) per 100,000 of population. 38% of the cases were over 65 years of age and 57% were between 15 and 65. The geographical distribution of reported cancer cases shows that Bethlehem governorate reports the highest figures with an incidence rate of 111.3 per 100,000 populations as shown in figure (2.1) (MOH, 2012).

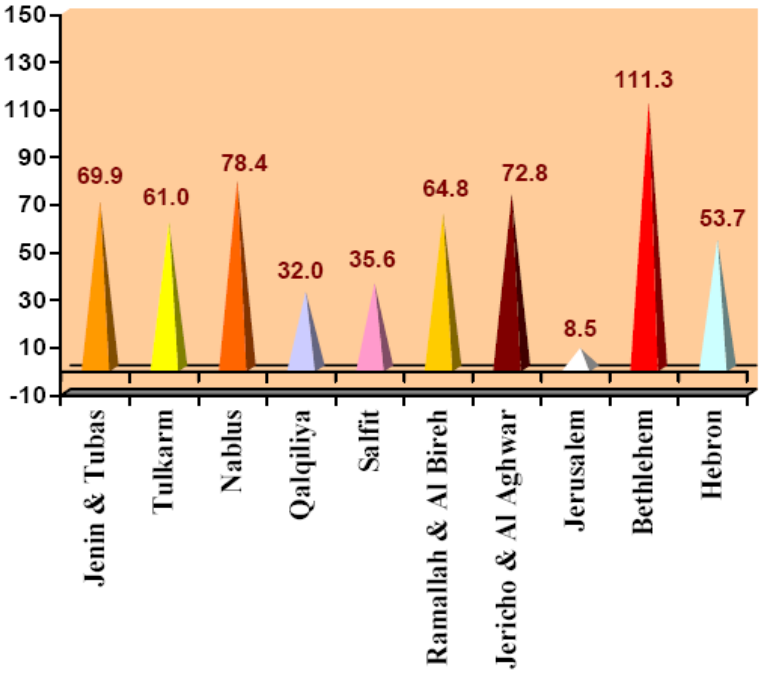

Figure (2.1): Distribution of Reported Cancer Cases Incidence Rate per 100,000 by Governorate, West Bank, Palestine, 2011. (MOH, 2012)

The most common cancer in Palestine is breast cancer (11.8%) and it is the first in females, while the first in males was the colon cancer (9.7%) and was the second overall cancer. The third was stomach cancer (9%) as shown in figure (2.2) (MOH, 2012).

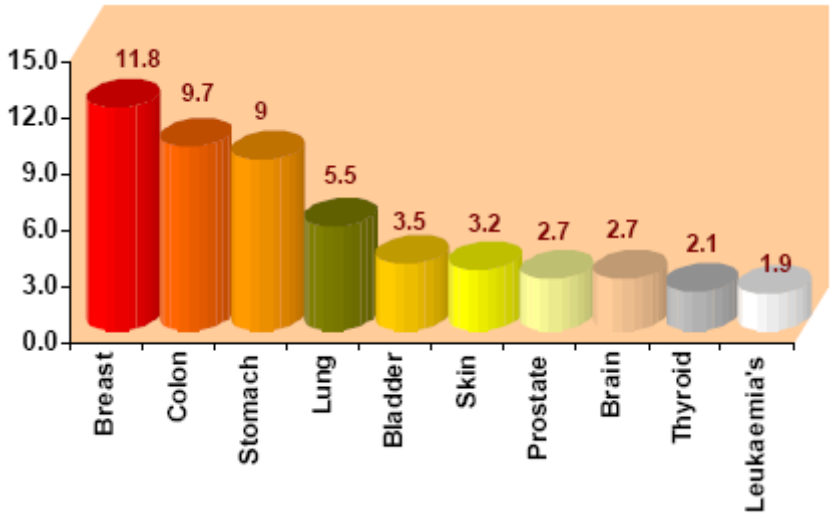

Figure (2.2): Most Common Cancer Cases, West Bank, Palestine, 2011. (MOH, 2012)

As cancer is the second leading cause of death in Palestine and in the region (MOH, 2012; Bingley & Clark, 2009). This represents a significant need for Palliative Care service in the Middle East region, including Palestine (Bingley & Clark, 2009). The national health strategy vision is to have "Better quality of life for the Palestinian people through controlling cancer prevalence in Palestine" (National Strategy for Cancer Prevention and control, 2009).

2.2.6. Quality of Life (QoL):

WHO defines QoL as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, and standards and concerns. It is a broad-ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationships to salient features of their environment" (WHO, 1997; Bowling, 2003).

The Center for Disease Prevention and Control (CDC) define QoL as "a broad multidimensional concept that usually includes self-reported measures of physical and mental health" (CDC, 2012 b).

Health related quality of life (HRQoL) is defined as "individual's definition of their overall satisfaction with life, or, a sense of personal psychological, physical and social well-being in being self-determining, independent and satisfied with control of disease processes" (O'Connor, 2004).

It has been discussed that (HRQoL) researches have shown the human side of cancer care and played a strong role as a predictor for survival. As well as, they helped in the decision making process for both the physician and the patient, throughout weighing costs and benefits of the deferent care modalities. (Schwartz and Sprangers, 2002)

2.2.7. Palliative Care (PC):

WHO defines Palliative care as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable

assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications." (WHO, 2012).

Meier and Brawley (2011) articulated Palliative care (PC) as a "broad construct defining a continuum that serves patients and families from the time of diagnosis with a chronic or acute progressive illness throughout the entire course of the disease". Early PC intervention, in accordance with the usual standard treatment for cancer was found to have better outcomes such as better QoL, mood, and survival (Yennurajalingam et al, 2010). It can be provided in hospital or outside it, and it emphasizes on expert and professional symptoms management (Meier and Brawley, 2011).

The goal of PC is to prevent and relieve suffering to achieve the best QoL for cancer patients; it also includes the family members in this endeavor. This expands the traditional model of disease treatment to include the goal of aiming for better QoL and functions for patient and family (Theofilou, 2012).

PC is considered as human right in many universal declarations. Of these declarations are the Universal Declaration of Human Rights for the right to standard living and healthy well-being, equal access to preventive, curative and palliative health services,

avoidable pain management, and essential drugs. The goal is to have PC and pain treatment on the agenda of the policy makers in each country health system (Breitbart, 2011). It is a public health strategy adapted by the WHO since 1990, who produced the WHO public health model for palliative care (Stjernsward et al, 2007a). (Figure: 2.3)

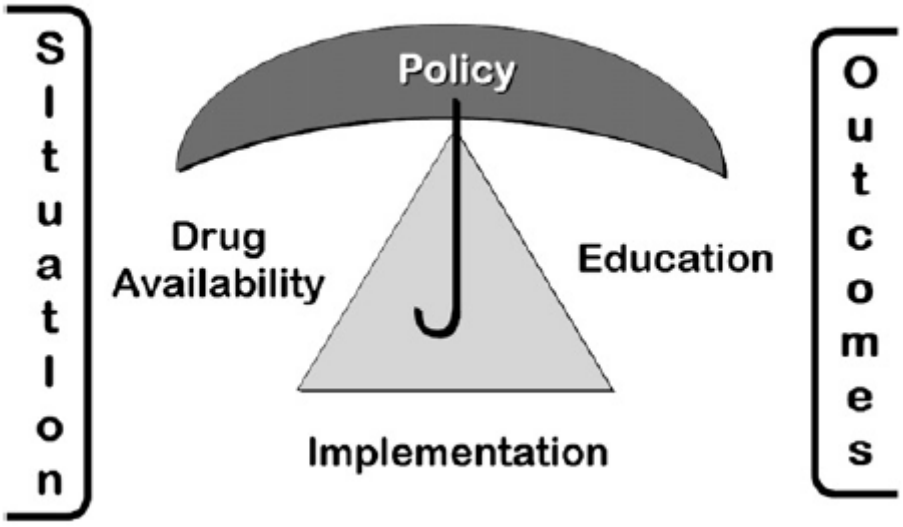

Figure (2.3): WHO Public Health Model for Palliative Care (adapted from Stjernsward et al, 2007a).

It is a public health issue to deal with people with cancer in the proper way (Sepulveda et al, 2002). This has special concern as cancer is the second leading cause of death in Palestine (MOH, 2012), and as palliative care and pain control is considered as one of the human rights (Breitbart, 2011).

The WHO defined gaps to bridge in the way to implement PC programs. Of these; are considering PC as a priority public health problem, by countries, and integrating it into the national health policies. As well, it advocated for key components of comprehensive PC programs such as policy development, education and training, drug availability, and providing good quality care (including home-based care) (Sepulveda et al, 2002; and Stjernsward et al, 2007a).

2.2.8. Pain:

Pain is considered one of the most important symptoms when talking about cancer. As well, it is considered one of the main factors that have an apparent effect on the QoL of patients with cancer. Pain is defined in many ways, one of the reliable and simple ones is “An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (IASP, 2011).

2.2.9. QoL Domains:

There are several dimensions of QoL of cancer patients. Here are some definitions of those domains of the QoL as defined by Schwartz and Sprangers (2002); first, Physical function was defined as “the ability to perform a range of activities of daily living”. On the other hand, Symptoms were said to be “patients’ subjective perceptions of an abnormal physical or psychological state”. Also, Functioning are “assessments of ability to perform specific tasks or functions, such as physical, social, emotional, and role functioning”. Furthermore, General health perceptions are “patients’ global perceptions about their health and include the values patients attach to different symptoms or functional impairments”. And finally, Overall QoL is “a measure of life satisfaction that may be unrelated to health”. For example, overall QoL may be strongly influenced by factors such as an individual’s economic and employment status, family situation, or the political environment (Schwartz and Sprangers, 2002).

2.3 Previous Studies Review

2.3.1. QoL and Influencing Factors:

Major associations with health related quality of life (HRQoL), in neighboring Arab country, were found with age, stage of cancer, radiotherapy treatment, and fatigue (Alawadi and Ohaeri, 2009). On the other hand, in two seperate studies in Iran, it was found that no correlation is present between QoL and age, sex, marital status, duration of disease, economic conditions, educational level, and occupational function; but, with

cycles of chemotherapy (more than two cycles) (Dehkordi et al, 2009 and Heydarnejad et al, 2011)). In a third one in Turkey by Pinar et al (2003) they found that duration of the disease and type of cancer, presence of metastasis, and type of treatment had no effect on QOL.

From a different view, Meier and Brawley (2011) pointed toward other studies, by Satin et al (2009) and Giese-Davis et al (2011) that presented depression as independent predictor of shortened survival. While Alawadi & Ohaeri (2009) found that younger Kuwaiti patients with breast cancer had lower (poorer) HRQoL scores, and that social functioning had the highest proportion of variance for GQoL. Other predictors were role function for physical function and vice versa, and cognitive for emotional function and vice versa. The financial difficulty had highly significant prediction of GQoL ($P< 0.007$) and social functioning (Alawadi and Ohaeri, 2009). Internationally, Scott et al (2007) found that the role and social functioning aspects have more apparent effect on QoL in Islamic countries.

Pain and Fatigue

Bostrom et al (2003) concluded that pain has a negative impact on QoL, especially on physical health. This pain usually increases towards the final stages of life, and they concluded that it is an unnecessary burden, which can be prevented.

This was also apparent in a multi center cohort prospective study that was done in Thailand. Thienthong et al (2006) found that a change of scores of pain of at least three points out of 10 had a significant statistical and clinical effect on the QoL of 520 cancer patients who was included in their study. The conclusion of this study suggests the high importance of pain management for better QoL of cancer patients.

Furthermore, Meier and Brawley (2011) argued that a review of 52 studies, which were reviewed by Beuken-van Everdingen in 2007 in their study “Prevalence of pain in patients with cancer: A systematic review of the past 40 years”, found that pain prevalence among cancer patients was 53%; with 64% prevalence among patients with advanced stages, and rating of pain as moderate to severe in one third of those who reported it. In addition to that, pain was associated with adverse outcomes such as depression, functional decline, and patient misery (Meier and Brawley, 2011). It can

happen in cluster with other symptoms, such as fatigue, insomnia, and mood disturbance, and negatively affect QoL and functional status of cancer patients (Cheng and Lee, 2010).

Regionally, Alawadi & Ohaeri (2009) found in their study of Kuwaiti cancer patients that the commonest problem areas were, also, pain, dyspnea, sleep disturbance, and poor appetite. As well, Fatigue found to have the highest correlation ($r=0.21$, $P<0.01$) with GQoL in the same study (Alawadi & Ohaeri, 2009). Better QoL was also found in patients with "*all-low*" cluster of four symptoms experience; including fatigue and pain (Pud et al, 2008). Internationally, Scott et al (2007) found in their Meta analysis study that fatigue is the most strongly associated factor with overall QoL. While Heydarnejad et al (2011) found the Iranian patients with pain have lower QoL.

Demographic Factors

Guner et al (2006) found in their study of the demographic factors effects on Turkish cancer patients that the total QoL mean scores were lower in men, illiterate patients, and those unsatisfied with their income. The lowest scores were in the over 65 years of age. In another study in Turkey by Pinar et al (2003) the results concluded that sociodemographic factors contribute to poorer QoL of cancer patients, namely they found that older cancer patients have lower QoL. Additionally, in another Turkish study, statistically significant relationship was found between QoL of cancer patients and education and employment status (Uzun et al, 2004).

In Turkey, older cancer patients believed that cancer is the end of the road and had low expectations of themselves as well of the society, the thing that negatively affected their QoL (Guner et al, 2006). Also, Koo et al (2012) found that elderly patients with advanced cancer have different QoL scores that tend to be worse than younger patients upon assessment using (EORTC) QLQ-C15-PAL and (EORTC) QLQ-C30 tools. On the contrary, Alawadi & Ohaeri (2009) found in their study of Kuwaiti cancer patients that there is more symptom intensity and worse functioning in younger patients.

Furthermore, highest QoL was in unmarried, in Turkey, as they have less responsibility by living with the family and gaining its support. While worst QoL was in widows as they lack the support of both family and spouse (Guner et al, 2006). Also, they

discussed that better QoL in educated patients may was due to better coping mechanisms or better access, finding and benefiting from resources. In the same prospect, the Illiterate patients had the lowest QOL scores (Pinar et al, 2003).

Financial burden has its effects also. Higher income was associated with better QoL. This was explained by Guner et al (2006) who said that patients with the higher income have better ability to find resources in less burden and stress. As well, Alawadi & Ohaeri (2009) found significant association of cancer with financial burden on cancer patients and their families, even though, treatment is free of charge. But they also stressed the social system support; they said that family social support and institutional support have a role in improving psychosocial wellbeing of those patients.

Clinical Factors

In the study of Kuwait, 59% of the cancer cases were in stages III and IV. Those with advanced disease had worse functioning; especially role function. As well, radiotherapy treatment found significantly associated with more fatigue (Alawadi and Ohaeri, 2009). On the other hand, in the study of Turkey by Pinar et al (2003) they found that duration of the disease and type of cancer, presence of metastasis, and type of treatment had no effect on QOL. However, hospitalized patients had lower QOL scores than patients treated on an outpatient-basis (Pinar et al, 2003).

2.3.2. Local, Regional and International Studies on QoL:

In a regional study in Kuwait, the GQoL found to be 45.3% with poor to average functioning (Alawadi & Ohaeri, 2009). In Turkey, Pinar et al (2003) measured GQoL, using different measurement tool (Multidimensional Quality of Life Scale-Cancer 2; MQOLS-CA2), to be 66.2 out of 100 points. In a study in Iran, QoL was fairly favorable (66% of cases) or favorable (23%) in cancer patients. it was found that the most common problems in Iranian patients to be fear about future, thinking about the disease and its consequences, impatience, and depression (Dehkordi et al, 2009).

Moreover, most of cancer patients, in the Middle East region, prefer to die at home due to presence of multiple traditional and social reasons. This stresses the need for home-

based services as a high priority in the health care system for better QoL (Silbermann, 2012).

In Palestine particularly, Bailony et al (2010) in their study; Cancer registration and healthcare access in West Bank, found that the concentration of cancer cases is in the districts that are considered metropolitan and where the referral hospitals are located.

Also, it was found in a non-published study done to assess factors influencing QoL of breast cancer patients in Palestine that marital status, economic status, and level of education were not significantly associated with QoL of those patients. Furthermore, it found that cancer in Palestine is diagnosed at late stage, and the surveyed sample had high spirituality beliefs (Samar & Saca, 2009).

As well, one study was done in 2010 to measure the QoL of 70 Palestinian cancer patients (Thweib, 2011). Results found that the QoL of Palestinian cancer patients is low in all QoL domains. More intense symptoms were found when compared with regional countries. This study stressed the importance of palliative care service for Palestinian cancer patients. the factors that were found to be associated with global quality of life (GQoL) and QoL domains for the Palestinian cancer patients were pain, gender, fatigue, income, and cancer stage (Thweib, 2011).

Nevertheless, palliative care is not present in Palestine yet, and it is not integrated within the health care system (Khleif & Shawawreh, 2011; Khleif, 2010; and Bingley & Clark, 2009). One study findings illustrated the main problems in the region in lack of fund or governmental support, and lack of awareness for need for such service among the public as well as the policy makers and professionals (Bingley & Clark, 2009).

The main areas for attention are professional training, public awareness, health policies regarding opioids use and dispensing, accessibility to essential PC drugs, and integrating palliative care into the health system, service provision and health education (Khleif & Shawawreh, 2011; Khleif, 2010; Bingley & Clark, 2009).

Silbermann (2012) discussed the culture of taboo and stigma of cancer and its pain. He said that people in this region consider it as part of disease and accept it, they use non-pharmacological modalities. The stress is on assessment of pain and distress to be routine practice. He concluded that of the barriers to PC are also the protective attitudes of the family of patient.

Scott et al (2007) in their international Meta analysis study about the effects of geographical and cultural aspects on the study tool; EORTC QLQ-C30 questionnaire, found that there is effect of these aspects among different cultural groups, which has its implications for international comparisons that shows differences between cultures.

On the other hand, a qualitative study conducted in Canada by Shahidi, Bernier and Cohen (2010) found eight domains upon content analysis of 110 answers of terminally ill cancer patients that affect QoL. These were physical condition and symptoms, psychological status, existential, relationships and support, quality of care, physical environment and living facilities, hobbies and daily activities, and finances.

2.3.3. Palliative Care: *…way to better QoL…*

Stjernsward et al (2007a) discussed that it is estimated that 7 million new cancer cases each year are not cured and die within a year of diagnosis, 60% of cancer patients suffer from significant pain, and 35 million people around the world are in need and can benefit from palliative care (PC) service.

It is recommended in the literature that to recognize the value of PC there is need for competent palliative medicine. This can be done through including PC requirements in the training programs of oncology trainees, and through system redesigns that has PC as essential part of its standard cancer care, protocols, and delivery models. This will need, off course, necessary investments in resources; both human and logistic (Meier and Brawley, 2011). The tragedy is the non-availability of PC for most of the world's population (Stjernsward et al, 2007a).

Meier and Brawley (2011) discussed the need for palliative care for better QoL for cancer patients and their families. They argued that palliative care should be for all patients with cancer and not only at the end-of-life care or what so called hospice care; as the later focus on caring of patients with limited life expectancy and mainly provided at home.

And so, palliative care medicine and practitioners work with other specialists on providing care to patients with curative and life-prolonging therapies (Theofilou, 2012; Meier & Brawley, 2011). Furthermore, the need for earlier and greater involvement of

PC in the treatment of cancer was argued, as a result of the accumulated evidence of benefits of PC in alleviating symptoms distress in those patients and improving outcomes of care (Meier and Brawley, 2011) and provide them with better QoL (Stjernsward et al, 2007a).

In this context, Meier and Brawley (2011) stressed the importance of promoting quality of care for cancer. They suggested new delivery and payment models aiming for promoting quality of care which may increase the incentives toward whole-person quality care.

On the other hand, Bakitas et al (2009) Compared, in their randomized controlled trial, participants receiving usual oncology care, and those who received a nurse-led, palliative care-focused intervention in the fields of physical and psychosocial aspects. They found statistically and clinically significant effects of nursing-led palliative care interventions on better QoL and mood of patients with advanced cancer.

Patients with cancer have many symptoms. On top of that are the physical symptoms including pain, which are highly prevalent in those patients, and have a major impact on many aspects of quality of life. This contradicts with the aim of palliative care (Mercadante et al, 2000). In their studies, Temel et al (2010) and Meier and Brawley (2011) found that early palliative care along with standard oncologic treatment resulted in better quality of life, mood, and prolonged survival. While Paci, et al (2001) found that QoL measures can be used to assess the outcome for patients who are involved in palliative care service.

Furthermore, PC is not only associated with better QoL of cancer patients themselves, it is also found to play a role in protecting the family and care givers of those patients. Meier and Brawley (2011) explored other studies findings of increased mortality and post-traumatic stress and grief disorders in family and caregivers of died cancer patients. So, PC is needed for the whole context of the patient.

From a different perspective, unnecessary suffering and costs for patients, families, and society in general are related to lack of good policies. Stjernsward et al (2007b) suggested development of national cancer control policy in order to integrate PC into the health care system and as a priority aspect in the national health plan. And then, to

incorporate PC and pain management in service delivery for cancer patients, which improves their QoL (Uzun et al, 2004).

But unfortunately, Silbermann (2012) explained that the Middle East countries still lack governmental policies that recognize PC. The patients, mostly, prefer to die at home due to presence of multiple traditional and social reasons in the Middle East region. This stresses the need for home-based services as a high priority in the health care system planning (Silbermann, 2012).

Lamas& Rosenbaum (2012) explained that the root of the problem, in a way or another, lays in physician's perception about palliative care, as many physicians believe that discussing pain control is admitting defeat; they are afraid of treating pain as they are afraid of patients' addiction to morphine.

This clearly stresses the need for PC services of cancer patients in Palestine in order to improve their QoL and decrease their suffering, as well as their families and caregivers. The implications, off course, are far beyond the mere patient. It is for the benefit and effectiveness of the whole health care system.

2.4 Studies reviewing the Assessment Tool (EORTC QLQ-C30)

HRQoL is an essential component in the care of cancer and chronic diseases. Generating data about QoL is accessible by using a valid and reliable tool to extract the data from its source; which is the patient perceptions (Theofilou, 2011). Patients are seen as the best possible source of data on the impact of treatment (Schwartz and Sprangers, 2002).

Theofilou (2012) discussed the factors necessary to choose a tool, among over 1000 available tools, to measure patient perception of QoL. Of the many factors he discussed are considering the aims and reasons for outcome, coverage of item of interest, validity and reliability, respondent item burden, patient-related factors in palliative care, and the concept of spirituality; in other words, an instrument with robust psychometrics and valid collection methods, and when it is disease-specific.

Theofilou (2012) discussed most frequently used tools to measure QoL in general and specific diseases patients. He compared the development, validity, and reliability of

those tools. The conclusion is the (EORTC) QLQ-C30 tool, that is used for this research, ranged of the best instruments among other tools, and ranged from good to excellent in its rating for validity and reliability. Dehkordi et al (2009) consider it as the most widely applicable tool.

The EORTC quality of life questionnaire (QLQ) is an integrated system for assessing the health related quality of life (HRQoL) of cancer patients. The core questionnaire is the product of more than a decade of collaborative research. More than 2200 studies so far used it, with less than 2% of missing data (Fayers et al, 2001). This tool was developed over data collected from centers in 13 countries and it is specific to measure QoL in cancer patients. Its item scores are linearly transformed to a range from 0 to 100 (Theofilou, 2012), and is based upon the widely applied Likert method of summated scales (Fayers et al, 2001).

Alawadi & Ohaeri (2009) and Thweib (2011) choose it for its reliability and validity in diverse cultures including Arab countries, availability of data body to compare own results with, and availability of ready Arabic translation of the tool by the original author. It has a scoring manual with it that we used to score out data and enter it to the statistical software Statistical Package for Social Sciences (Fayers et al, 2001).

Other studies have validated this tool, for example; Awad et al (2008) assessed the psychometric properties of the Arabic version of the tool for Arabic-speaking populations and concluded that it is a reliable and valid tool for assessment of QoL in Arab patients with cancer. The questionnaires' validity was confirmed using "known group comparisons," which showed that the QLQ-C30 discriminated between mastectomy and lumpectomy patients on the emotional and cognitive function scales ($P < 0.001$). (Awad et al, 2008). Questionnaire reliability was assessed using Cronbach's alpha coefficient, in which the values were all >0.7, with the exception of cognitive function and pain in the QLQ-C30 (Cronbach's alpha 0.67 and 0.51, respectively). (Awad et al, 2008).

Safaee & Dehkordi (2007) examined reliability and validity of it for use in Iran, and Uwer et al (2011) studied responsiveness of it in colorectal cancer patients in France. They found it more responsive in chemotherapy patients, particularly in functional scales.

As described in the tool scoring manual, there are a number of ways to ease the interpretation of QLQ-C30 results. One can report the raw scores in addition to the transformed scores. Scores range from 0 to 100; a higher score represents a higher ("better") level of functioning or GQoL, or a higher ("worse") level of symptoms. The author of the tool recommended the use of Global health status / QoL scale (Q29 and Q30) as the overall summary measure of QoL (Fayers et al, 2001).

Many previous studies used the cutoff scale score of 33% to interpret the results (Thweib, 2001; Alawadi & Ohaeri, 2009). That was adopted based on suggestions from an empirical general population study (as cited by Alawadi & Ohaeri (2009) from Fayers PM: Interpreting quality of life data: population-based reference data for the EORTC QLQ-C30, 2001). We are also using these methods of categorizing patients QoL scores in this study.

It has been argued that the use of these measuring tools provided evidence which can be used for evaluating the needs and feelings of the cancer patients, the thing that is crucial for professionals, as well as, managers in the health care system (Theofilou, 2012).

2.5 Economic and Public Perspective of Palliative Care

Millions of people around the world, with a majority of occurrence in developing countries, have great suffering and economic hardship due to life threatening illnesses such as cancer. The key feasible alternative to the urgent needs of those people to improve their QoL, according to WHO global perspective, is to develop an effective, low-cost approach of palliative care service of good quality and coverage. The best way to do so, in countries with strong family support and poor health infrastructure, is home-based palliative care (Sepulveda et al, 2002; and Stjernsward et al, 2007a).

Assessment of QoL and interpretation of its results and data is important for supporting the generation of policies and legislations. It will also help in allocating resources, building strategic plans, and monitor effectiveness of community based interventions (Theofilou, 2011). As well, Rogers et al (2012) found in UK cancer patients that more financial burden is associated with cancer and resulting in poorer QoL.

Outcome measurement, which are based on measured reported outcome by patients, has major role in improving, not only the quality of palliative care, but also its efficiency and availability. It is considered an effective tool to assess and monitor care and QoL in palliative care services for cancer patients. Furthermore, this can help focusing on improving quality of services (Theofilou, 2012).

Schwartz and Sprangers (2002) and Theofilou (2011) discussed that data of the assessment of QoL can help in comparisons between different treatments the thing that can be used in prioritizing actions, allocating resources, evaluating effectiveness, measuring outcomes, and analyzing cost-utility. This is particularly apparent when looking at the modern technologies and its subsequent increase in the costs of medical interventions, and the need for the proof of effectiveness and quality of the care provided.

Meier and Brawley (2011) discussed that PC teams can support mobilization of resources in the community for sustainable and safe living environment for patients and families after discharge from hospitals. Additionally, such interventions have low costs and no or minimal risks. PC service found to reduce unnecessary use of hospitals, diagnostics, treatments, and invasive procedures. Rogers et al (2012) concluded that multi disciplinary teams play an important role in addressing patients' needs early and providing them with advice for better access to the best benefits and least costs.

Husseini et al (2009) discussed the high cost of care; indirect loss of production, and the societal stress. This is the result of the high morbidity and mortality of cardiovascular and cancer diseases as major killers in Palestine. They added that a large proportion of the expenditure on health in Palestine is on expensive curative care outside the area.

Meier and Brawley (2011) stressed the importance of promoting quality of care for cancer. They suggested new delivery and payment models aiming for promoting quality of care which may increase the incentives toward whole-person quality care. As many therapies to control cancer are ineffective and expensive (Stjernsward et al, 2007a).

It is recommended in the literature that, to recognize the value of PC, there is need for competent palliative medicine. This can be done through system redesign that has PC as essential part of its standard cancer care, protocols, and delivery models. This will need,

off course, necessary investments in resources; both human and logistic (Meier and Brawley, 2011).

Husseini et al (2009) argued that the challenge of chronic diseases, including cancer, is not the only one. The national economy, strategic planning, health-care policy formulation, and national priority setting are affected by the Israeli occupation. The geographic and administrative fragmentations of occupied Palestine, the military checkpoints and barriers to movement, and the separation wall and many other fences and barriers are all having their damaging effects on the health care system abilities and deliverability. In addition to adding to the physical suffering of patients and the financial costs since they have to travel for treatment (Husseini et al, 2009; Physicians for Human Rights website, 2012).

2.6 Summary

QoL is subjective in nature. At the same time it can be reliably and validly measured, but keeping the focus on the patient as the primary source of information (Schwartz and Sprangers, 2002). As health care providers and as leaders in palliative care, we need to measure patients' perceptions of their well-being, or QoL. This is important for both; for having the ability to perform high quality patient care by professionals, and for being accountable for monitoring and measuring the impact of services and treatments by the program managers (Theofilou, 2012).

Throughout this chapter of literature review we explored a wide variety of studies as well as articles and books. We came out with the conclusion that HRQoL assessment is an important public health tool (Theofilou, 2011). It was clearly apparent the need for palliative care (PC) services for cancer patients in Palestine in order to improve their QoL and decrease their suffering, as well as their families and caregivers. The implications, off course, are far beyond the mere patient entity; it is for the benefit, efficiency, and effectiveness of the whole health care system.

To conclude, the literature review was supporting to the rational that we conducted to justify the aim for this research. The national and international data revealed almost consensus on the value of assessment of QoL of cancer patients in monitoring care, proposing actions, regulating policies, saving costs, and alleviating suffering of cancer patients and their families. This is uniquely applicable to Palestinian cancer patients, especially in the present health care system that is struggling in many ways; explicitly the absence of palliative care from the system.

Table (2.1): Summary of reviewed studies of QoL of cancer patients.

#	Study	Main Purpose	Methodology *(design, sample, place, tool)*	Data Analysis	Findings
1	Outcome Measurement in Palliative Care; QoL. (Theofilou, 2012)	To focus on best practices in selecting QOL instruments, as well as review and evaluate current QOL instruments.	Review of available literature for QoL measurement tools.	Comparative analysis of tools based on validity & reliability.	Choosing a tool depends mainly on the type of study, condition to be measured, and the researcher orientation to scientific and clinical situation. Collaborations between clinicians and researchers greatly enhance the feasibility and capacity for implementing outcomes programs. More accurate determination HRQoL when disease specific instruments are used.
2	Patients' perception of the financial impact of head and neck cancer and the relationship to health related quality of life. (Rogers et al, 2012)	To ask patients about the financial burden of having head & neck cancer, and to explore its relation with HRQoL.	Cross-sectional survey 447 respondents Mersey region, UK Questionnaire	Statistical analysis for responses to the questionnaire.	Patients with worse physical and social emotional functioning experienced more notable financial burden, more difficult life circumstances and greater financial difficulty and loss in income, more dissatisfaction with how well they took care of their own financial needs. This has a serious impact on financial aspects of patients' lives and seems to be associated with a poor HRQoL.
3	Quality of Life of Palestinian Cancer Patients. (Thweib, 2011)	To highlight the concept of QOL for Palestinian cancer patients through providing an understanding about influences of cancer and chemotherapy on QOL of cancer patient.	Cross-sectional descriptive study. 70 cases. Palestine. EORTC QLQ-C30.	Statistical analysis using SPSS software for descriptive, correlations, and means tests.	Results about QOL were low in all aspects; most of them were less than the half of full function, and, more intense symptoms and negative effects were found to be in Palestinian cancer patients
4	Factors affecting quality of life in cancer patients undergoing chemotherapy. (Heydarnejad et al, 2011).	To evaluate the QoL in cancer patients with solid tumors and at the different chemotherapy cycles.	Cross-sectional descriptive study. 200 cases. Iran. EORTC QLQ-C30.	Statistical analysis using SPSS software for descriptive, correlations, and means tests.	A chemotherapy cycle may improve QoL in patients with solid tumors. Patients with pain have lower QoL.

5	Effects of pain, fatigue, insomnia, and mood disturbance on functional status and quality of life of elderly patients with cancer. (Cheng & Lee, 2010)	Describes prevalence of pain, fatigue, insomnia, and mood disturbance in elderly cancer patients. The inter-correlations among these symptoms and the relationship to functional status and QoL during cancer therapy.	Cross-sectional study used secondary data from a convenience sample of 120 patients in Hong Kong, China.	Statistical analysis for descriptive and correlations.	Pain, fatigue, insomnia, and mood disturbance are highly prevalent in elderly patients who undergone cancer therapy. These four symptoms may occur in a cluster and may negatively influence elderly patients' functional status and QoL during cancer therapy.
6	Factors influenced QoL for women with breast cancer in Palestine. (Samara et al, 2009)	to investigate the main factors that influence the quality of life for women with breast cancer in Palestine	Cross-sectional descriptive study. 108 cases. Palestine. Ferrell and Grants (1995) QoL assessment tool.	Descriptive statistics.	Marital status, economic status, and level of education were not significantly correlated to the four domains of quality of life. Cancer in Palestine is diagnosed at late stage. Women had higher mean scores according to their spiritual well being.
7	Health - related QoL of Kuwaiti women with breast cancer: a comparative study using the EORTC QoL Questionnaire. (Alawadi & Ohaeri, 2009)	To highlight the health-related QoL of Kuwaiti women with breast cancer, in comparison with the international data, and assessed the socio-demographic and clinical variables that predict the five functional scales and GQOL scale of the QLQ – C30.	Cross-sectional descriptive study. 348 cases. Kuwait. EORTC QLQ – C30 and its breast specific module (BR-23).	Statistical analysis using SPSS software for descriptive, correlations, and means tests.	Kuwaiti women had clinically significantly poorer GQoL and functional scale scores, and more intense symptom experience. Younger women had poorer HRQOL scores. In regression analysis, social functioning accounted for the highest proportion of variance for GQOL.
8	QoL in Cancer Patients undergoing Chemotherapy (Dehkordi et al, 2009)	To describe the QoL in cancer patients with solid tumors and at different chemotherapy cycles.	Cross-sectional descriptive study. 200 cases. Iran. EORTC QLQ-C30	Statistical analysis using SPSS software for descriptive, correlations, and means tests.	There were no correlation between the QoL and age, sex, marital status, and duration of disease, economic conditions, occupational function, and patients' educational level. Nevertheless, a significant correlation was found with the no. of chemotherapy cycles (>2cycles)
9	Cardiovascular, Diabetes & Cancer in the occupied Palestinian territory. (Husseini et al, 2009)	To identify any relevant scientific reports about chronic diseases in the occupied Palestinian territory.	Analysis report of available data based on specific search strategy and selection criteria. Palestine.	Gathering data from different resources, national surveys, and epidemiological studies. Then	Heart disease, cerebrovascular disease, and cancer are the major causes of morbidity and mortality in the occupied Palestinian territory, resulting in a high direct cost of care, high indirect cost in

			Search through Medline (1966–2008) with specific search terms.	completeness and quality of data assessed & compiled	loss of production, and much societal stress.
10	Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer. (Bakitas et al, 2009)	To determine the effect of a nursing-led intervention on quality of life, symptom intensity, mood, and resource use in patients with advanced cancer	Randomized Controlled Trial of Multi-component, psycho-educational intervention case control study. 322 patients. NCI, USA. Tools: Functional Assessment of Chronic Illness Therapy for Palliative Care, Edmonton Symptom Assessment Scale, Center for Epidemiological Studies Depression Scale.	Statistical analysis for intervention effects, descriptive, correlations, and means tests.	Compared with participants receiving usual oncology care, those receiving a nurse-led, palliative care–focused intervention addressing physical, psychosocial, and care coordination provided concurrently with oncology care had higher scores for quality of life and mood, but did not have improvements in symptom intensity scores or reduced days in the hospital or ICU or emergency department visits.
11	Validation of the European Organization for Research and Treatment of Cancer Quality of Life Questionnaires for Arabic-speaking Populations. (Awad et al, 2008)	To assess the psychometric properties of the Arabic version of the EORTC general QoL questionnaire (QLQ-C30) and of the breast cancer-specific questionnaire (QLQ-BR23).	Cross-sectional. 87 patients. United Arab Emirates. EORTC QLQ-C30, QLQ-BR23.	Statistical analysis using SPSS software for descriptive, correlations, and means tests.	Arabic versions of the EORTC QLQ-C30 and QLQ-BR23 are reliable and valid tools for assessment of quality of life in Arab patients with cancer.
12	The relationship between overall quality of life and its sub-dimensions was influenced by culture: analysis of an international database. (Scott et al, 2007)	To investigate whether geographic and cultural factors influence the relationship between the global health status quality of life (QL) scale score of the EORTC QLQ-C30 questionnaire and seven other subscales representing fatigue, pain, physical, role, emotional, cognitive, & social functioning	Meta analysis study. Large international database of QLQ-C30 responses.	Linear regression model used to predict QL scale scores. Using STATA software Included interactions between geographical/cultural groupings & seven other scale scores.	The results provided evidence that different cultural groups may emphasize different aspects of their QoL. This has implications for studies using QoL questionnaires in international comparisons.

13	QoL and socio-demographic characteristics of patients with cancer in Turkey. (Guner et al, 2006)	To determine whether a relationship exists between QoL and the sociodemographic characteristics of gender, age, marital status, educational level, occupation, and level of income in patients with cancer in Turkey.	Exploratory study using a convenience sample. 620 cases. Turkey. Face-to-face interviews to fill Rolls-Royce Quality-of-Life Scale.	Statistical analysis for descriptive, correlations, and means tests.	Men, older adults, widowed spouses, patients with lower levels of education, housewives, and those with lower income had lower QOL scores.
14	Quality of life in women with breast cancer in Turkey. (Uzun et al, 2004)	To determine QoL of Turkish women with breast cancer, and to examine whether QoL was related to sociodemographic or clinical variables.	Descriptive study. 72 cases. Turkey. Quality of Life Scale (QoLS), and the Visual Analogue Scale (VAS)	Descriptive statistics.	Two sociodemographic variables (educational background and employment status) were related to QoL of women with breast cancer. And affected QoL in varying degrees.
15	Assessment of QoL in Turkish Cancer patients. (Pinar et al, 2003)	To evaluate the QoL and affecting factors on it in Turkish cancer patients.	Cross-sectional study using self-report questionnaire. 188 cases. Turkey. Turkish version of Multidimensional Quality of Life Scale-Cancer 2.	Statistical analysis using SPSS software for descriptive, correlations, and means tests.	Sociodemographic factors rather than cancer related factors could contribute to poorer QoL. Associations found between poorer QoL and older age, illiterate, and hospitalized patients.

Chapter Three

Conceptual Framework

3.1 Conceptual Framework

Do the Palestinian cancer patients have their QoL preserved? Does this affected by any unique cultural, social, ideological or political factors?

Is the **QoL** of the Palestinian cancer patients affected by **pain and other symptoms** management in **hospitals** in the West Bank in its specific **socio-demographic** context?

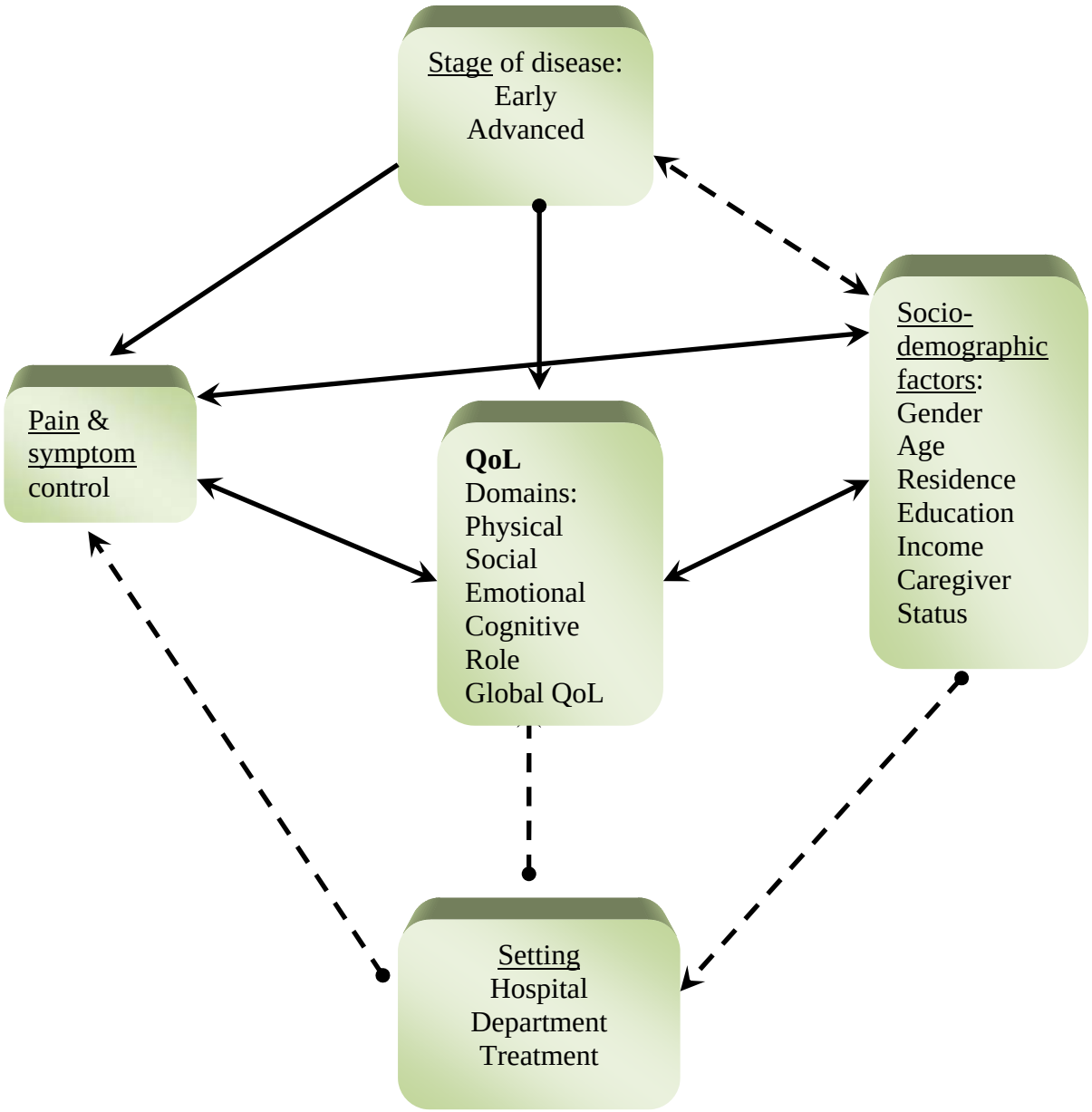

Figure (3.1): Conceptual framework of the study; different factors affecting QoL in anticipated direct and indirect relationships.

3.2 Conceptual Definitions

Conceptual Framework

It is “a conceptual model broadly presents an understanding of the phenomenon of interest and reflects the assumptions and philosophic views of the model’s designer. Conceptual models can serve as springboards for generating research hypotheses” (Polit & Beck, 2003).

The current study conceptual framework represents the different factors affecting QoL of the cancer patient in Palestine. The model shows that QoL and its domains are affected directly by the sociodemographic factors, stage of the disease, and level of pain and symptom control. Also, they are affected indirectly by care setting. Moreover, there are some relationships between the different independent factors as shown in figure (3.1).

QoL Definition

WHO defines QOL as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, and standards and concerns. It is a broad-ranging concept affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships, and their relationships to salient features of their environment” (Bowling, 2003).

Pain Definition

Pain is defined in many ways, one of the reliable and simple ones is “An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (IASP, 2011).

QoL Domains (Functions) definitions:

Physical function: “the ability to perform a range of activities of daily living”.

Symptoms: “patients’ subjective perceptions of an abnormal physical or psychological state”.

Functioning: are “assessments of ability to perform specific tasks or functions, such as physical, social, emotional, and role functioning”.

General health perceptions: are “patients’ global perceptions about their health and include the values patients attach to different symptoms or functional impairments”.

Overall QoL: is “a measure of life satisfaction that may be unrelated to health. For example, overall QoL may be strongly influenced by factors such as an individual’s economic and employment status, family situation, or the political environment.”

(Schwartz and Sprangers, 2002).

3.3 Operational Definitions

Dependant variables:

EORTC QLQ C-30 (EORTC) provides a Scoring Manual which includes the operational definitions (EORTC, 2009).

Global Quality of Life (GQoL):

29. How would you rate your overall health during the past week?
30. How would you rate your overall quality of life during the past week?

Physical Function (PF):

1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?
2. Do you have any trouble taking a long walk?
3. Do you have any trouble take a short walk outside of the house?
4. Do have to stay in bed or a chair for most of the day?
5. Do you need help with eating, dressing, washing yourself or using the toilet?

Role Function (RF):

6. Were you limited in doing either your work or other daily activities?
7. Were you limited in pursuing your hobbies or other leisure time activities?

Social Function (SF):

26. Has your physical condition or medical treatment interfered with your family life?
27. Has your physical condition or medical treatment interfered with your social activities?

Emotional Function (EF):

21. Did you feel tense?
22. Did you worry?
23. Did you feel irritable?
24. Did you feel depressed?

Cognitive Function (CF):

20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?
25. Have you had difficulty remembering things?

Financial Difficulties (FI):

28. Has your physical condition or medical treatment caused you financial difficulties?

Fatigue (FA):

10. Did you need to rest?
12. Have you felt weak?
18. Were you tired?

Nausea & Vomiting (NV):

14. Have you felt nauseated?
15. Have you vomited?

Pain (PA):

9. Have you had pain?
19. Did pain interfere with your daily activities?

Dyspnea (DY):

8. Were you short of breath?

Insomnia (SL):

11. Have you had trouble sleeping?

Appetite Loss (AP):

13. Have you lacked appetite?

Constipation (CO):

16. Have you been constipated?

Diarrhea (DI):

17. Have you had diarrhea?

Independent variables

These include sociodemographic and clinical variables:

Gender: male or female.

Age: from 18 and above; this was classified to three age groups which are below 40, from 41 to 64, and above 65 years old.

Educational level: either illiterate, primary school, secondary school, or university.

Residence: either in a city, village, or camp.

Governorate: either one of Palestine governorates; Jenin, Tobas, Tulkarm, Nablus, Qalqelia, Salfit, Ramallah & Beirah, Jericho, Jerusalem, Bethlehem, and Hebron.

Income: classified as either less than 2000 NIS, from 2000 to 4000 NIS, or more than 4000 NIS.

Caregiver: either the patient is self care independent, depends on family member to take care of him/ her, depends on a paid person to take care of him/ her, or any combination of the previous three options; self care and family member, self care and paid person, family member and paid person, or the three options.

Marital Status: either the patient is single, married, or other than that; which includes divorced, widow, separated, or any other option.

Living condition: either living alone, with family, or other.

Housing: either the patient is living in a rented house or an owned one.

Place of treatment: is the hospital; either in outpatient or in-patient departments. The three hospitals are Augusta Victoria Hospital, Watani Hospital, or Beit Jala Hospital.

Department: is the ward; inpatient or outpatient.

Stage of disease: will be determined from the patients files based on the medical diagnosis and staging. The first and second stages will be considered as early disease, the third and fourth stages of cancer patients will be considered late disease.

Setting variable: there are three main settings that treat patients with cancer in Palestine; these are Beit Jala and AL Watani governmental hospitals, and Augusta Victoria non-governmental hospital. In each setting patients are either in out-patient or in in-patient departments.

Duration: is the time span of treatment; less 3 months, more than 6 months, or in between the two periods.

Region: is the area of the West Bank of Palestine; north, middle, or south.

Chapter Four

Methodology

4.1 Introduction

In this chapter we explored and discussed the design of this research and the sampling methodology that was followed to identify and approach the sample cases of cancer patients who participated in this study. Settings where the study took place and some of their characteristics and data were discussed as well.

4.2 Research Design

In this study a triangulation design is used through quantitative descriptive correlation and qualitative phenomenological methods. In the qualitative part, the living experiences of cancer patients from different areas of Palestine were explored. That was done through direct in-depth-interviews by the researcher with participants who attended for cancer treatment in one of the selected centers.

Schwartz and Sprangers (2002) cited in their article from Krause and Jay (1994) that qualitative research revealed that the frame of reference defer from respondent to respondent while answering the questions in the QoL questionnaires. They added that the specific references vary by age and education.

In the quantitative part, we used a cross-sectional descriptive design using a self-filling questionnaire to collect the data from cancer patients from different settings in Palestine. This was used to describe different variables affecting the GQoL, QoL domains functions, and symptoms of cancer patients. This method was chosen as it describes these variables from the patients' point of view, it is feasible and applicable to do by the researcher, and because this area of study was never been studied in such extensive and in-depth way and using such method is good for doing such primary studies. This type of study is preferable when there is a time limitation (Polit & Beck, 2003).

4.3 Sampling Methodology

Population

The exact numbers of cancer cases in the West Bank of Palestine is not known, due to the scarcity and inaccuracy of information available and reported. Palestinian cancer registry is not systematically updated and hospitals did not have accurate count of active cancer patients on treatment. Upon contacting the Palestinian MOH, the Palestinian health information center, and the three cancer treating hospitals, the researcher came out with estimation of the population of the study.

Based on the statistics of MOH annual health report (2011), there were 1350 new cancer cases in 2010 (of which, 1278 cases are above 15 years old), and 1312 cases in 2009, with mortality of 727 deaths in 2010 from cancer. Also, by keeping in mind that the course of treatment for cancer is from six months to two years (so the patient is either cured or dead, and in both cases is out of the population count); this makes the estimated count of active cancer cases at the time of planning for this study to be around 2000 cases.

Selection criteria

Inclusion criteria

- Cancer patients above the age of fifteen years old.
- Cancer patients attending and have files in any of the three main hospitals for cancer treatment; Beit Jala hospital in Bethlehem, Al-Watani hospital in Nablus, and Augusta Victoria hospitals (AVH) in Jerusalem.

Exclusion criteria

- Any patient who have any surgical intervention within the last thirty days, or
- Any patient who have systematic disease or mental incompetence, which may prevent him/ her from being able to answer the questionnaire or complete the interview.

Sample

A purposive sample of 10 participants was chosen for the qualitative part based on saturation of data, as evaluated by the researcher and the supervisor. This is acceptable method in qualitative research. Polit & Beck (2003) stated that the principle of data saturation occurs when themes and categories in the data become repetitive; that is no new information can be generated by further data collection.

A convenient sample of 323 respondents was chosen for the quantitative part. This sample size was calculated to achieve statistical significance (0.05 error margin), and using the online sample size calculators (Raosoft, 2012; Survey System, 2012). Convenient sample use was obligatory due to unavailability of accurate data, no general data base to draw a random sample from, hospitals could not provide us with an exact number of active patients on treatment, and very poor information available for patients' contacts, addresses, or telephone numbers.

Moreover, samples from each setting were based on each hospital's staff estimation of the size of their patients from the total population of cancer patients. Estimation were; more than half for Beit Jala hospital, around one-third for AVH, and around one-tenth for Watani hospital. The data was collected during a period of three months.

4.4 Study Settings

There were two governmental hospitals included in the study; Beit Jala hospital in Bethlehem in the southern region and Al-Watani hospitals in Nablus in the northern region, and one non-governmental setting; Augusta Victoria hospital (AVH) in Jerusalem in the middle region of the West Bank (WB) of Palestine.

Beit Jala Hospital: is the main governmental center for cancer treatment in Palestine. Its capacity is 119 beds and treats all types of cancer and cancer patients, including pediatric patients. It has a separate oncology department of 25 in-patient beds. It has also a day care unit for chemotherapy for cancer patients. The hospital has out-patient oncology clinics four days per week. It is considered the referral hospital for cancer in the government and treats patients from all over the West Bank of Palestine (MOH, 2011).

Al-Watani Hospital: is a secondary governmental center to treat cancer patients. Its capacity is 55 beds and treats adult cancer patients only. There is no specific oncology department in it and patients are admitted to the medical ward. It has a day care unit that provides assessment, diagnosis, and treatment for patients (MOH, 2011).

Augusta Victoria hospital (AVH): is the only non-governmental center to treat cancer patients. It depends on referrals of patients from the government. It has been located in Jerusalem since 1950, and work on a mix of charitable and private bases. Its capacity is 164 beds and has nine major departments; including the cancer center that has medical, surgical and radiation units. It treats all types of cancers and patients, including children (AVH website, 2012).

4.5 Permissions and Ethical consideration

The Research Review Committee of the School of Public Health at Al-Quds University reviewed and approved this research. The Palestinian MOH was contacted for permission to access the two governmental hospitals (Annex 10), as well as Augusta Victoria hospital (Annex 9), and all of them allowed us access to patients' files and to conduct survey and interviews.

Patients consents were taken by informed consent (Annex: 8), either verbal or written, after full explanation of the study and its objectives. Patients were assured anonymity of participation, and confidentiality of the data collected. The qualitative part participants were also asked for agreement to voice record the interviews. All participants were aware of the fact that they can withdraw from the study (interview) at any time.

The permission to use the tool was also granted from the European Organization for Research and Treatment of Cancer (EORTC ), who developed it. The tool is free of charge for academic uses (EORTC, 2011). The researcher had contacted the EORTC by email and got the required permission and approval to use their assessment tool as shown in annex (7).

4.6 The Assessment Tools

The qualitative part study tool consisted of a list of questions. This list is prepared by the researcher, after thorough review of literature, and approved by the thesis supervisor, as well as enriched by the review of the experts in their validation process of the research tools. It consists of questions about QoL perception and determinants from the patients view point. These questions were somehow adapted from the questions of the QoL questionnaire and were as follows:

1. How did the disease affect your daily living? What are the interactions of the disease with your daily life?
2. How do you deal with the disease?
3. What are the arrangements you need to do in order to get health care services?
4. How do you evaluate the health care services you are receiving or had received?
5. What are the things / measures that should be available in order for you to have a high quality of life as a cancer patient?
6. How do you see, in general, the community/ social context view of cancer and cancer patient in Palestine?

The quantitative part study tool consisted of two sections. The first section is the demographic data including age, gender, educational level, place of residence, governorate of residence, monthly income, caregiver, marital status, living conditions,

house ownership, place of treatment, department of care, stage of disease, and duration of treatment.

The second section is measure of QoL of cancer patients by European Organization for Research and Treatment of Cancer (EORTC ). It has been translated and validated in 81 languages –one of them is Arabic. It is free of charge for academic uses (EORTC, 2011). This tool was used to assess QoL of cancer patients in the region, including Palestine, and found to be valid tool (Thweib, 2011). Moreover, Uwer et al (2011) found in their study of the responsiveness of the tool that the EORTC QLQ-C30 questionnaire is more responsive in patients receiving chemotherapy than other two tools designed to measure QoL. The questionnaires' validity was confirmed, in Arab population, using "known group comparisons," which showed that this tool discriminated between mastectomy and lumpectomy patients on the emotional and cognitive function scales ($P < 0.001$). (Awad et al, 2008).

EORTC Tool (Aaronson, 1993):

The European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire Core 30 (QLQC30) Version 3.0 consists of 30 items; 28 four-point scale items and two seven-point scale items. It consists of five multi-item scales measuring functionality in physical, role, social, emotional, and cognitive dimensions; three multi-item symptom scales measuring fatigue, pain, and nausea and vomiting; six single-item symptom measuring dyspnea, insomnia, appetite loss, constipation, diarrhea, and financial difficulties; and a global health and QoL scale (Theofilou, 2012; and Fayers et al, 2001).

Validity and reliability of the tool was tested in many cultures and languages (Safaee & Dehkordi, 2007; Theofilou, 2012; Dehkordi et al, 2009; Uwer et al, 2011), including Arabic language (Awad et al, 2008). Alawadi & Ohaeri (2009) and Thweib (2011) choose it for its reliability and validity in diverse cultures including Arab countries, availability of data body to compare own results with, and availability of ready Arabic translation of the tool by the original author.

National and regional studies (Alawadi & Ohaeri, 2009; Thweib, 2011) used the cutoff scale score of 33% to interpret the results of the QLQ-C30 questionnaire. That was

adopted based on suggestions from an empirical general population study (as cited by Alawadi & Ohaeri (2009) from Fayers PM: Interpreting quality of life data: population-based reference data for the EORTC QLQ-C30, 2001). We are using the same method of categorizing patients QoL scores in this study.

Scoring linear conversion was done according to the EORTC QLQ-C30 scoring manual. Scores range from 0 to 100; a higher score represents a higher ("better") level of functioning or GQoL, or a higher ("worse") level of symptoms (Fayers et al, 2001).

Pilot Study

A pilot study was done to verify the research tool and questions, and to identify any special concerns or uniqueness of cancer patients in Palestine. It was conducted in one of the hospital settings and included 15 patients for the quantitative survey and one patient for the qualitative interview.

The results of this pilot study were used to modify the questions in order to best suit the local cancer patients especially in relation to data collection procedure. Minor changes were found to be necessary after the pilot study. These changes were limited to rephrasing some words for clarity reasons and consistency.

Validity and Reliability of the Questionnaire

Validity of the questionnaire for use with Palestinian cancer patients was assured by experts' review of the questionnaire and its items. The questionnaire was reviewed by a specialized palliative care doctor, a specialized palliative care nurse, an oncologist, a social worker, and an expert in research methodology and design (Annex 11). Experts confirmed suitability of the questionnaire items and questions to Palestinian cancer patients, and that they are measuring what they are intended to measure. Off course their inputs in both the qualitative and quantitative questions were incorporated and integrated into the study tools and produced the final tool for the research.

As well, validity was confirmed through calculating the intra class correlation coefficient of the questionnaire items (questions) with the total degree of the tool, as

shown in table (4.1) below. The results showed high statistical significance (P<0.0001, 2-tailed), with strong positive correlation (range from r=0.28 to r=0.79) in all items, except of questions 29 and 30 were it was strong negative correlation (r= -0.61 and -0.53 respectively). This resembles the direction of the correlation but preserving the strength; as the intra class correlation coefficient is like the interclass correlation (Pearson's), which is confined to the interval (-1, +1) (Wikipedia, 2012).

Table (4.1): Intra class correlation coefficient of the questionnaire items with the total degree of the tool.

#	Questions / Items	Pearson Correlation (r)	P value (2-tailed)
1	Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	0.54	<0.001
2	Do you have any trouble taking a long walk?	0.62	<0.001
3	Do you have any trouble take a short walk outside of the house?	0.63	<0.001
4	Do have to stay in bed or a chair for most of the day?	0.65	<0.001
5	Do you need help with eating, dressing, washing yourself or using the toilet?	0.57	<0.001
6	Were you limited in doing either your work or other daily activities?	0.61	<0.001
7	Were you limited in pursuing your hobbies or other leisure time activities?	0.64	<0.001
8	Were you short of breath?	0.57	<0.001
9	Have you had pain?	0.68	<0.001
10	Did you need a rest?	0.66	<0.001
11	Have you had trouble sleeping?	0.58	<0.001
12	Have you felt weak?	0.78	<0.001
13	Have you lacked appetite?	0.60	<0.001
14	Have you felt nauseated?	0.56	<0.001
15	Have you vomited?	0.41	<0.001
16	Have you been constipated?	0.50	<0.001
17	Have you had diarrhea?	0.28	<0.001
18	Were you tired?	0.77	<0.001
19	Did pain interfere with your daily activities?	0.79	<0.001
20	Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	0.68	<0.001
21	Did you feel tense?	0.65	<0.001
22	Did you worry?	0.70	<0.001
23	Did you feel irritable?	0.59	<0.001
24	Did you feel depressed?	0.63	<0.001
25	Have you had difficulty remembering things?	0.42	<0.001
26	Has your physical condition or medical treatment interfered with your family life?	0.58	<0.001
27	Has your physical condition or medical treatment interfered with your social activities?	0.61	<0.001
28	Has your physical condition or medical treatment caused you financial difficulties?	0.51	<0.001
29	How would you rate your overall health during the past week?	-0.61	<0.001
30	How would you rate your overall quality of life during the past week?	-0.53	<0.001

Reliability; internal consistency or responsiveness to change, was examined by using Cronbach's alpha test. Cronbach's alpha determines the internal consistency or average correlation of items in a survey instrument to gauge its reliability. However, an alpha of 0.7 or above is normally considered to indicate a reliable set of items (Greasley, 2008; Awad et al, 2008). In this study, the overall Cronbach's Alpha reliability test was 0.87 and this gives the tool a high degree of reliability, see table (4.2) for detailed results.

Table (4.2): Internal reliability of questionnaire (Cronbach's Alpha test)

	No. of items	Cronbach's Alpha
Overall reliability	30	**0.87**
GQoL	2	0.88
Physical Function (PF)	5	0.84
Role function (RF)	2	0.90
Emotional function (EF)	4	0.87
Cognitive function (CF)	2	0.53
Social function (SF)	2	0.89
pain (PA)	2	0.82

Awad et al (2008) tested the reliability of the QLQ-C30 using Cronbach's alpha coefficient, in which the values were all >0.7, with the exception of cognitive function and pain (0.67 and 0.51, respectively), and they concluded that the tool is reliable for use in Arab population to assess QoL of cancer patients (Awad et al, 2008).

It is noticeable that cognitive function reliability is low, as well as in regional studies, the thing that maybe due to decreased ability of the tool to assess this aspect or inability of the respondents to understand it well. On the other hand, it is usually not easy for the person to admit of having decreased cognitive ability, the thing that maybe reflected in this low reliability score.

4.7 Data Collection

Qualitative part: The researcher interviewed 10 participants using face-to-face in-depth-interview technique. Each one of them was interviewed separately in private place. The interviewees were chosen from the three settings; AVH, Watani, and Beit Jala hospitals.

The in-depth-interviews were conducted during May and June 2012. The length of each interview ranged from 30 to 50 minutes. All interviews were recorded on digital voice recorder. The recorded material was saved and coded by number, place of interview, sex of patient, age of patient, place of residence, diagnosis, date and time of interview, and the duration of each interview.

Quantitative part: Self-administered questionnaires were distributed to 350 patients who were waiting for oncology out-patient clinics, taking chemotherapy session in the day case department, or admitted as in-patients. That was done during May and June 2012. Each participant was asked for willingness to participate and if was enrolled before in the study; this guaranteed no repetition or duplication of cases. 323 questionnaires were returned producing 92% response rate. Privacy of patients guaranteed by offering them to fill in the questionnaire themselves or by the researcher on one-to-one bases. Data, then, entered into the Statistical Package for Social Sciences software (SPSS 19).

4.8 Data Analysis

Qualitative Data Analysis

The researcher used the verbatim method of transcribing the recorded in-depth-interviews. Then the transcriptions were reviewed by three experts; an expert in research and research methodologies with interest and experience in analyzing in-depth-interviews, a specialized palliative care nurse, and the researcher. Also, the thesis supervisor reviewed the end-result themes as well.

The analysis of the data was based on using the thematic analysis method based on the study objectives and the research questions. Firstly, the three reviewers produced the themes independently through repeated readings of the interviews transcriptions, coding of sentences and phrases, and eliciting ideas and themes. Then, the reviewers conducted

meetings to discuss the interviews and the coding, and then, agreed on common themes for each question based on the answers of the participants.

Analysis was for unique factors (themes) related to QoL of cancer patients in Palestine. The generated themes were distributed in the table of themes which contained the main themes, sub-themes, divisions under sub-themes, and quotations of participants' responses (Annex: 2). Then, these themes were processed for some features like repetition and the most common issues. These were arranged to show frequencies and ranking and used in the discussion part to support some of the significant results that were generated by the quantitative analysis.

Quantitative Data Analysis

The statistical package for social sciences (IBM® SPSS® version 19) was used to enter the raw data. The EORTC manual was used for coding the data. ANOVA, t-test, Chi square, and Pearson's correlation tests, to test relationships and correlations between GQoL, QoL domains, and Symptoms with socio-demographic and condition factors, were used. Then, predictors of GQoL, QoL domains, and the most significant symptoms and issues related to them were produced using regression analysis. Tables and figures used, where statistically significant data presented only within the text body.

4.9 Summary

This study used a triangulated (qualitative, quantitative) methodology in assessing the QoL of the cancer patients in the West Bank of Palestine. This research collected the data through structured in-depth-interviews and through a questionnaire tool. The data was processed manually and through SPSS statistical package testing. This was done according to international and local standards of research, taking into consideration the ethical and scientific rules and obligations. Reliability and validity of the study tool was assured through statistical and experts testing, as well as through extensive literature review. That supported the study and its importance and vitality for cancer patients in Palestine.

Chapter Five

Results

5.1 Introduction

This chapter consists of two parts. Part one is presenting quantitative results. It will explore the demographic characteristics of the respondents. Other items are also presented such as diagnosis diversity, places, services for treatment outside the main hospitals facility, and needs as expressed by the patients themselves.

Presentation of GQoL, QoL domains functioning, and symptoms averages and percentages are follow. Some classifications according to region and treating hospital are done in

correlation to severity of three items; GQoL, pain, and financial difficulties. A 33% cut-off point classification was used to identify the percentage of the respondents who are considered to have either the severe symptoms (>66%) or the poor QoL (<33%). This classification was based on other studies, (Alawadi & Ohaeri, 2009; Thweib, 2011), for better understanding of the results of the QoL assessment tool.

Part two is presenting qualitative results. These include presenting the demographic data of the participants from different regions and governorates of the West Bank of Palestine. Then the main themes resulted from these interviews are presented. Consensus and agreements on most apparent themes and issues were presented, then presentation of resulted subthemes and divisions from the main themes are articulated. Quotations for the most important and distinctive issues were also expressed.

5.2 Quantitative Results

This section includes the presentation of the quantitative socio-demographic data, and the results of the data generated from the EORTC QLQ-C30 tool including respondents' physical function (PF), social function (SF), role function (RF), cognitive function (CF), emotional function (EF), and symptoms of fatigue (FA), pain (PA), nausea and vomiting (NV), dyspnea (DY), constipation (CO), diarrhea (DI), insomnia (SL), appetite loss (AP), as well as financial difficulties (FI).

5.2.1. Socio-Demographic Characteristics:

The total number of the respondents involved in this study is 323 patients (92% response rate). Socio-demographic and financial characteristics, as well as characteristics related to their disease status and treatment related issues were explored and presented in this section.

Figure (5.1) shows the distribution of participants according to the governorate they live in. It shows that the majority of respondents are from the south (58.2%), while (17%) from the middle, and (19.4%) from the north of the West Bank of Palestine.

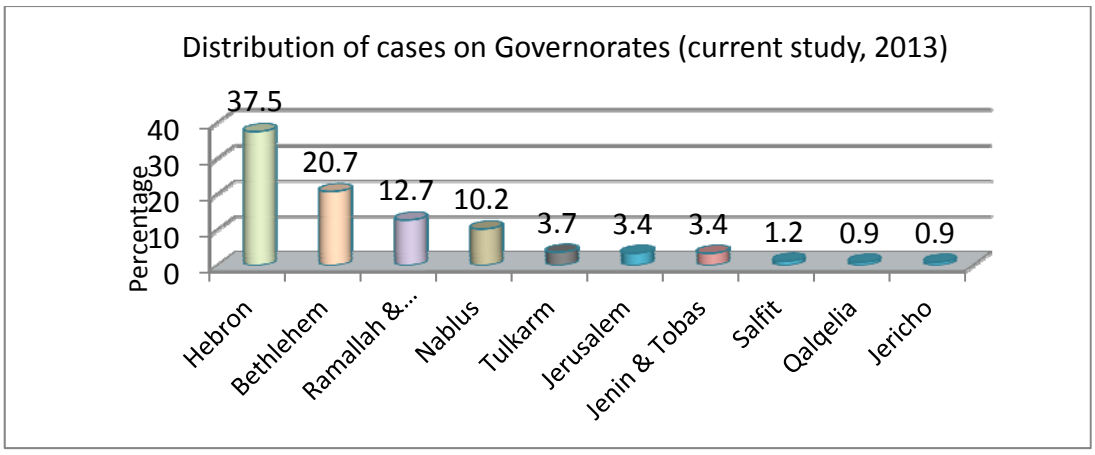

Figure (5.1): Distribution of participants according to district

Figure (5.2) shows the distribution of the cancer cases over the governorates of the West Bank of Palestine (MOH, 2011). In the current study the respondents' distribution is congruent with that of the MOH reported cases, with some minimal deviations.

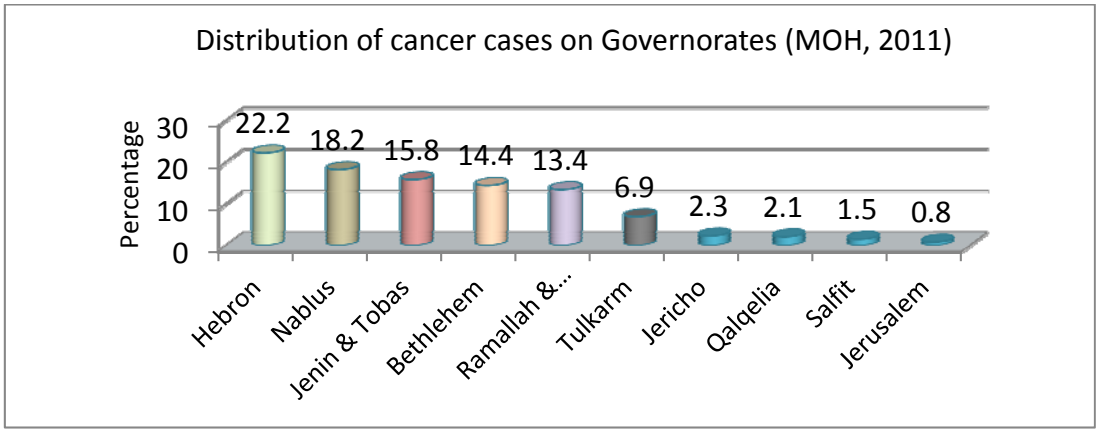

Figure (5.2): Distribution of cancer cases over governorates of West Bank of Palestine (source MOH annual report, 2011).

Socio-demographic characteristics for the participants in this study are presented in table (5.1). It shows that 58.2% are females, mean age is 52.7 years (SD=15.2), and the majority of cases are in the age group of 41 to 64 years (59.4%).

Of the total participants, majority had low education; 20.1% were illiterate, 37% had primary education, and only 13.2% had high education as shown in table (5.1). The table shows also that 55.4% of participants were from villages against 39.6% from cities, and only 4.7% from camps.

The majority of cases (75.2%) were very poor with an income less than 2000 NIS, 20.9% had income of less than 4000NIS, and only 3.9% of participants had income more than 4000NIS per month as shown in table (5.1). This means that 75.2% of the Palestinians have severe poverty. The Palestinian statistics determined the relative poverty line and the deep poverty line according to consumption patterns (for reference household consisted of 2 adults and 3 children) in the Palestinian Territory in 2012 of 2,293 NIS, and 1,832 NIS respectively. It showed poverty rate among Palestinian individuals of 17.8% in the West Bank (PCBS, 2012). This was due to loss of jobs by cancer patients after they got the disease in most of the cases.

Table (5.1): Socio-demographic characteristics of the respondents.

		Frequency	Percentage
Sex	Male	135	41.8
	Female	188	58.2
Age Group*	≤ 40 yrs	60	18.9
	41 - 64 yrs	189	59.4
	≥ 65 yrs	69	21.7
Educational level	Illiterate	64	20.1
	Primary	118	37.0
	Secondary	95	29.8
	University	42	13.2
Place of residence	City	125	39.6
	Village	175	55.4
	Camp	15	4.7
Monthly income	Less than 2000 NIS	234	75.2
	2000 - 4000 NIS	65	20.9
	More than 4000 NIS	12	3.9
Marital status	Single	38	11.8
	Married	247	76.7
	Other	37	11.5
Living condition	Living alone	26	8.1
	Living with family	292	90.7
	Other	4	1.2
House ownership	Rented house	27	8.4
	Owned house	296	91.6

*Mean age is 52.7 years (SD=15.2).

The study findings showed that marital status of participants was 76.7% married, 11.8% single, and 11.5% widow, divorced, or separated. Also, the majority (90.7%) is living with their families, and only 8.1% of participants are living alone, while some (1.2%) had other living conditions such as living in geriatric house or do not have place to live in. On the other hand, 91.6% of participants had owned their houses, while 8.4% were living in rented houses as shown in table (5.1).

Table (5.2) shows that the majority of respondents (62.2%) were treated at Beit Jala Hospital in Bethlehem, 29.7% were at Augusta Victoria Hospital in Jerusalem, and 8% at Watani Hospital in Nablus. The concentration of cancer cases was in the outpatient departments (73.7%), while the inpatients were 26.3%. The study revealed that most of the participants were on chemotherapy treatment (52.2%), and 36.2% had a combination of the all types of treatments, of which are 10.6% had used alternative medicine in accordance with their medical treatment.

Table (5.2): Place & type of treatment and the person taking-care of the cancer patients.

		Frequency	Percentage
Place of treatment	Beit Jala Hospital	201	62.2
	Watani Hospital	26	8.0
	AVH	96	29.7
Type of treatment	Chemotherapy	167	52.2
	Radiotherapy	17	5.3
	Surgical treatment	20	6.3
	Combinations	119	36.2
Department of care	Outpatient clinic	238	73.7
	In-patient ward	85	26.3
Person taking care of patient	Self caring	111	34.5
	Family member	132	41.0
	Paid person	1	0.3
	Both; self caring & Family member	78	24.2

Table (5.2) shows that 34.5% of participants are taking-care of themselves. But (41%) of the participants expressed that someone from the family members is taking care of them in their sickness, while 24.2% were taking care of themselves with help from a family member.

Table (5.3) shows that the majority of respondents (71.4%) were in advanced disease condition with (35.7%) in the third stage and (35.7%) in the fourth stage, while only (24.2%) in stage two and (2.5%) in stage one. This is higher than international figure for advanced stages (NCI, 2012).

Table (5.3): Stage of cancer and duration of treatment since diagnosis.

		Frequency	Percentage
Stage of disease	stage 1	8	2.5
	stage 2	76	24.2
	stage 3	112	35.7
	stage 4	112	35.7
	Unknown	6	1.9
Time span of treatment	less than 3 months	67	21.0
	3 - 6 months	53	16.6
	more than 6 months	199	62.4

In table (5.3) the duration of treatment for the participants was mainly longer than six months (62.4%), 21% less than three month duration, and 16.6% were between 3-6 months.

Table (5.4) shows the distribution of cancer diagnoses for the participants. The most common cancer is breast cancer (31.6%) of all cases (males and females) while colon cancer was 14.2% of all cases.

Table (5.4): Distribution of cancer Diagnoses among the sample of the study according to frequency of occurrence.

	Frequency	Percentage
Breast cancer	102	31.6
Colon cancer	46	14.2
Prostate cancer	21	6.5
Lymphoma	19	5.9
Leukemia	18	5.6
Stomach cancer	16	5.0
Lung cancer	14	4.3
Brain cancer	12	3.7
Skin carcinoma	11	3.4
Ovarian & Uterine	9	2.8
Thyroid cancer	6	1.9
Kidney cancer	6	1.9
Unknown	5	1.5
Other cancers	5	1.5
Laryngeal cancer	4	1.2
Pancreatic cancer	4	1.2
Gallbladder cancer	3	0.9
Bone cancer	2	0.6
Sarcoma	2	0.6
Esophageal cancer	1	0.3
Total	306	94.6

Figure (5.3) shows that; these results are in accordance with the national data for the first two most-common cancers in Palestine (MOH, 2011).

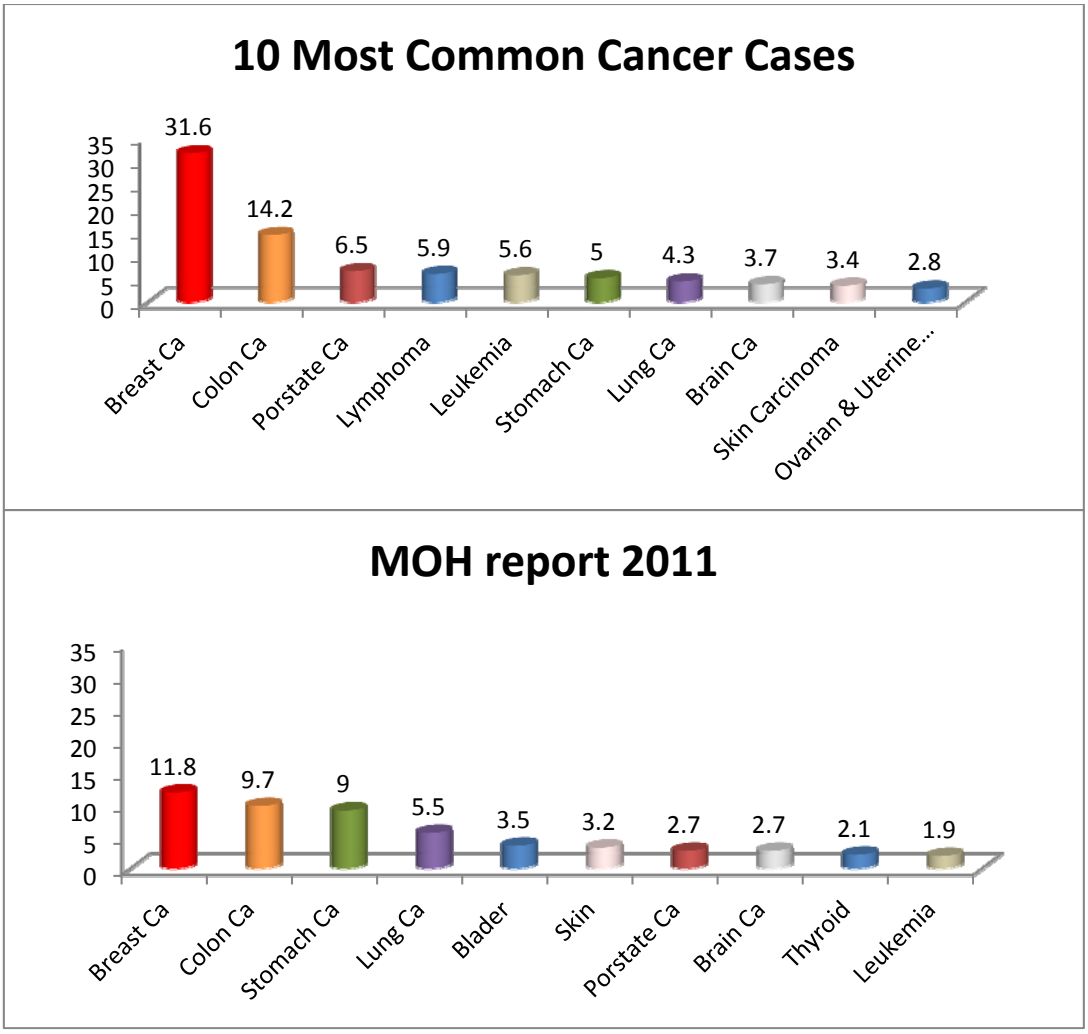

Figure (5.3): The 10 most common cancer types in current study, compared to those presented by MOH annual report, 2011.

5.2.2. Respondents' Needs for Other Services:

Table (5.5) presents the places that the participants are seeking for other services, in this study, beside the main hospital they are treated in. They articulated these places as alternative places to go to when they have needs for other services that are either not available at the hospital of treatment or because the hospital is far away. It shows that 18.9% used private services, 14.6% used governmental health services (GHS), and the

others used NGOs, abroad, UNRWA, Ministry of Social Affairs (MOSA), or religious entity. Nevertheless, the majority (35%) said "No Place" which not necessarily means the absence of the need, but the absence of the alternative.

Table (5.5): Other places used by participants besides the hospital of treatment.

	Frequency	Percentage
No place	113	35.0
Private center	61	18.9
GHS	47	14.6
Abroad	12	3.7
NGOs	7	2.2
UNRWA	6	1.9
MOSA	5	1.5
Religious entity	1	0.3
Total	252	78.1

In table (5.6), around 16% needed to do diagnostic testing outside the treating hospital. 15.2% needed to have treatment or medication outside the hospital for their symptoms such as pain. 5.3% needed to seek financial supports, 1.2% needed to have fluids and blood infusions, and 0.6% needed laboratory testing in other place. Nevertheless, 35% of participants did not use services outside the treating hospital; this does not necessarily mean the absence of the need, but the absence of the alternative.

Table (5.6): Other services used by the participants outside the hospital of treatment.

	Frequency	Percentage
No service	113	35.0
Diagnostic tests	52	16.1
Pain & symptoms meds and Rx	49	15.2
Financial support	17	5.3
Blood & fluids	4	1.2
Lab. tests	2	0.6
Total	237	73.4

The participants expressed the following (Table: 5.7) as their needs when they were asked for things that they needed throughout the course of treatment: (25.1%) expressed the need for financial aids in covering the expenses accompanied with disease, such as transportation, food, and accommodation, 12.1% needed medications and treatment such as chemotherapy, symptom management medications and 2.8% expressed the need for diagnostic facilities availability in their local area. However, 24.5% of respondents indicated that they need "nothing". This was noticed to be as a reflex to show dissatisfaction and anger with the available services for them.

Table (5.7): Needed services that are not available at the hospital of treatment as expressed by participants.

	Frequency	Percentage
Financial aids	81	25.1
No expressed needs	79	24.5
Availability of meds & Rx	39	12.1
Diagnostic facilities	9	2.8
Home nursing care	8	2.5
Psychosocial support	6	1.9
Non-distant treatment center	5	1.5
Less waiting time	3	0.9
Medical & Mechanical supplies	3	0.9
Health education	3	0.9
Transportation availability	3	0.9
Total	239	74

Other needs were home nursing care (2.5%), psychosocial support services (1.9%), non-distant hospital for treatment (1.5%), less waiting time especially in the outpatient clinics (0.9%), medical and mechanical supplies such as wheel chairs, artificial cosmetic parts, and disposables (0.9%), health education (0.9%), and availability of easy transportation (0.9%) especially in the presence of the separation wall.

5.2.3. Means for GQoL, Functions, and Symptoms:

Table (5.8) presents the mean of the global health status and QoL (GQoL) of the participating cancer patients. The average mean of GQoL was 41.8% (SD=26), this means less than half of the full GQoL, which means a very low mean. In this scale measure, the higher the percentage (from 0 to 100) is the better QoL for those patients.

Five other functions or QoL domains were measured also as shown in table (5.8). All the functions were below the half of the full function, except for cognitive function (60.5%). The average was for Physical function 48.5%, role function 48.8%, emotional function 46%, and social function 50%. The table also presents the number of participants in each domain and the standard deviations. This shows it clearly that the GQoL and other QoL domains are very low and under half of the full function in this scale.

Table (5.8): Means for GQoL and QoL Domains (Functions) for participants.

	N	**Mean***	Std. Error
Global health status (GQoL)	315	**41.8**	1.5
Physical functioning (PF)	300	**48.5**	1.6
Role functioning (RF)	314	**48.8**	2.2
Emotional functioning (EF)	306	**46.0**	1.7
Cognitive functioning (CF)	310	**60.5**	1.7
Social functioning (SF)	314	**50.0**	2.1

*Higher mean is better GQoL or better functioning.

The most distressing symptoms, of the eight symptoms measured for the participants in this study as shown in table (5.9), were fatigue (66.6%) and pain (63%). This is considered a very high score on this scale from 0 to 100, as the higher the result is the worse symptom to experience by cancer patients. Other symptoms were insomnia (56.4%), appetite loss (45.3%), dyspnea (37.2%), constipation (36.3%), nausea and vomiting (31.5%), and diarrhea (18.5%).

Table (5.9): Means for Symptoms and Financial difficulties for the participants.

	N	**Mean***	Std. Error
Fatigue (FA)	311	**66.6**	1.6
Financial difficulties (FI)	318	**64.6**	2.1
Pain (PA)	311	**63.0**	1.9
Insomnia (SL)	317	56.4	2.2
Appetite loss (AP)	317	45.3	2.2
Dyspnea (DY)	317	37.2	2.1
Constipation (CO)	319	36.3	2.3
Nausea & vomiting (NV)	311	31.5	1.9
Diarrhea (DI)	319	18.5	1.7

*Higher mean is worse symptoms or worse financial difficulties.

Table (5.9) shows mean for the expressed financial difficulties (64.6%) experienced by participants in this study. This represents a high financial burden added on the Palestinian cancer patients.

5.2.4. 33% Cut-Off point Classification:

The 33% cut-off point classification is used to identify the percentage of the sample that are either in the lower third or in the upper third of this classification. That is; those who are

considered to have either the severe symptoms (>66%) or the poor QoL (<33%). This classification was based on other studies, (Alawadi & Ohaeri, 2009; Thweib, 2011), for better understanding of the results of the QoL assessment tool results.

The next paragraphs present the results of the study in terms of QoL domains and symptoms using the 33% cut-off point classification.

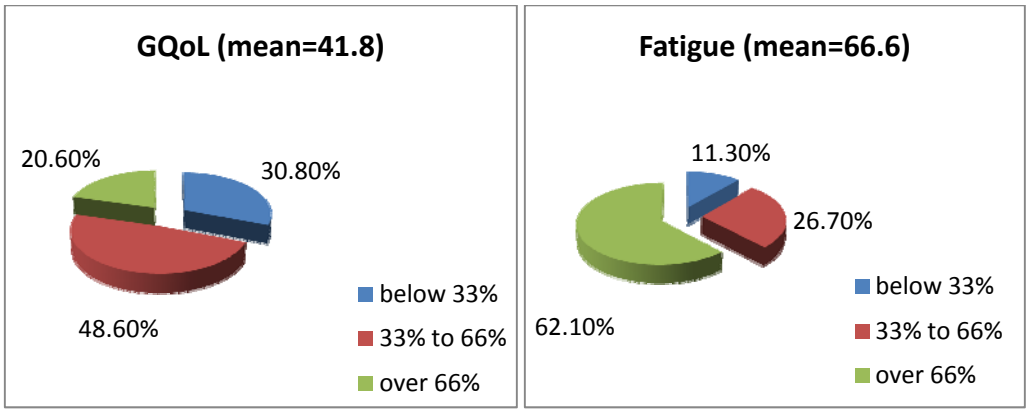

Figure (5.4): 33% cut-off point classification of GQoL and fatigue.

In figure (5.4), around 62% of participants had severe fatigue (>66% cut-off point), and 48.6% of participants had moderate GQoL (33% to 66%).

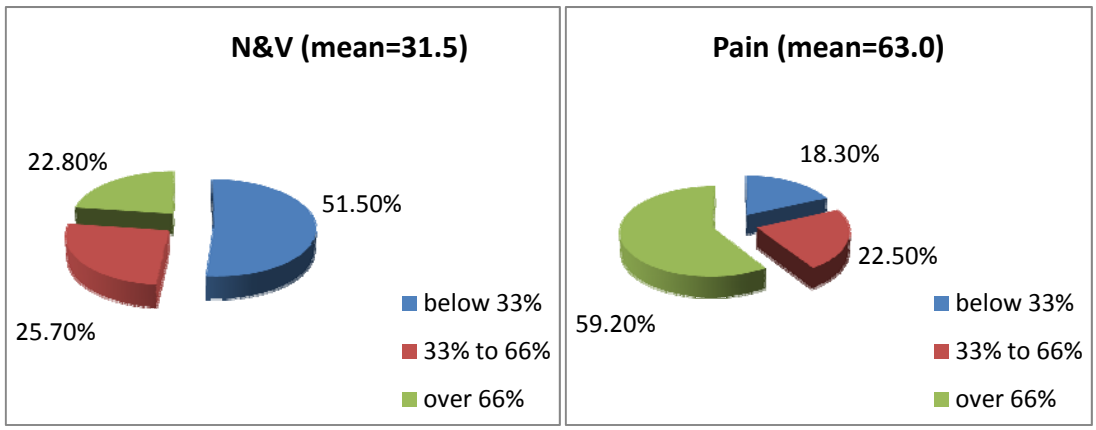

Figure (5.5): 33% cut-off point classification of nausea & vomiting and pain.

In figure (5.5), 51.5%of participants had mild nausea and vomiting (<33%), and 59.2% of participants had severe pain (>66%).

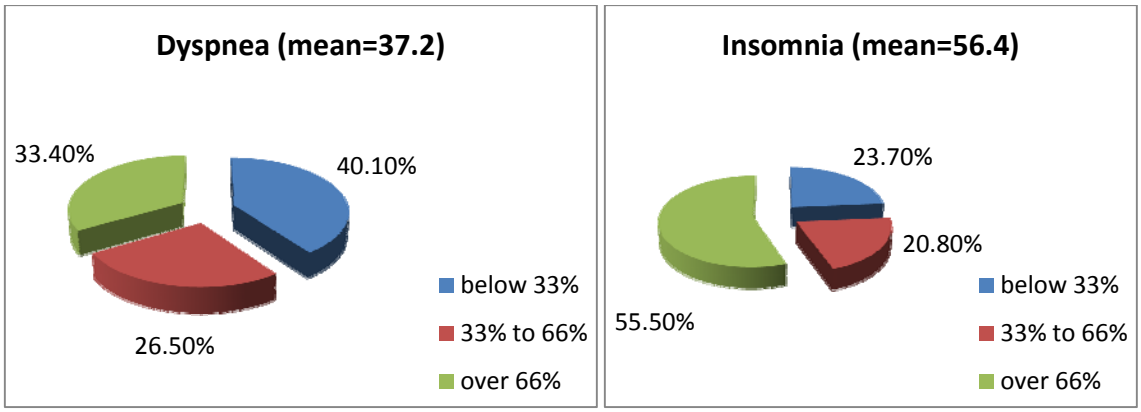

Figure (5.6): 33% cut-off point classification of dyspnea and insomnia.

In figure (5.6), 40.1% of participants had mild dyspnea (<33%), and 55.5% of participants had severe insomnia (>66%).

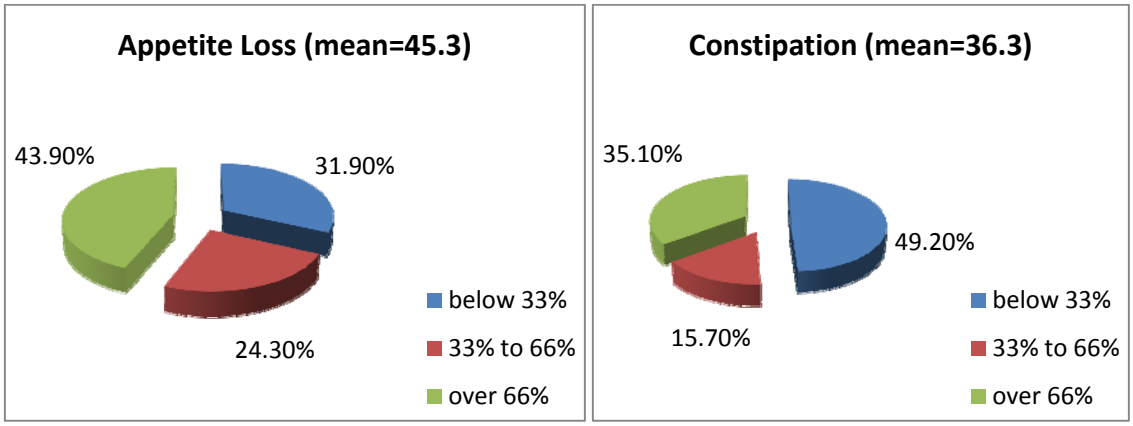

Figure (5.7): 33% cut-off point classification of appetite loss and constipation.

In figure (5.7), 43.9% of participants had severe loss of appetite (>66%), and 49.2% of participants had mild constipation (<33%).

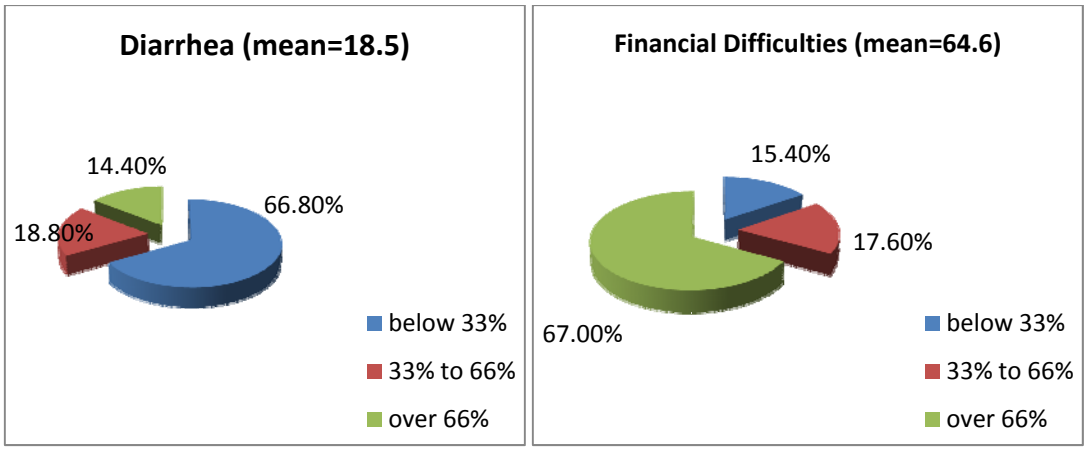

Figure (5.8): 33% cut-off point classification of diarrhea and financial difficulties.

In figure (5.8), 66.8% of participants had mild diarrhea (<33%), and 67% of participants had severe financial difficulties (>66%).

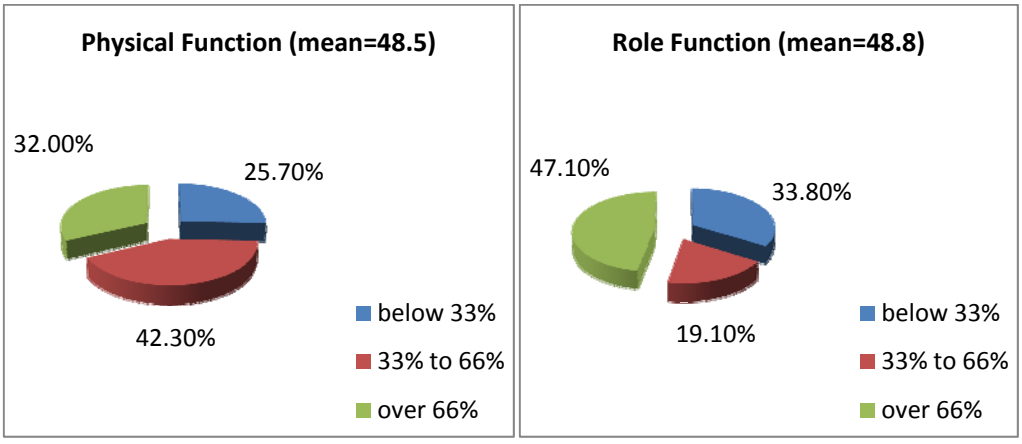

Figure (5.9): 33% cut-off point classification of PF and RF.

In figure (5.9), 42.3% of participants had moderate physical function (between 33% and 66%), and 47.1% of participants had a good role function (>66%).

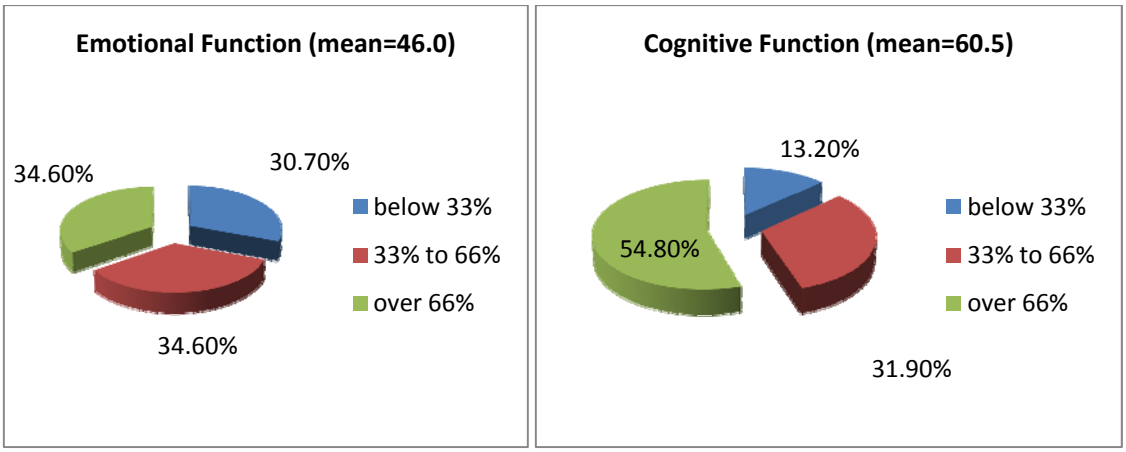

Figure (5.10): 33% cut-off point classification of EF and CF.

In figure (5.10), the participants were distributed between moderate and good emotional function (34.6%), and 54.8% of participants had a good cognitive function (>66%).

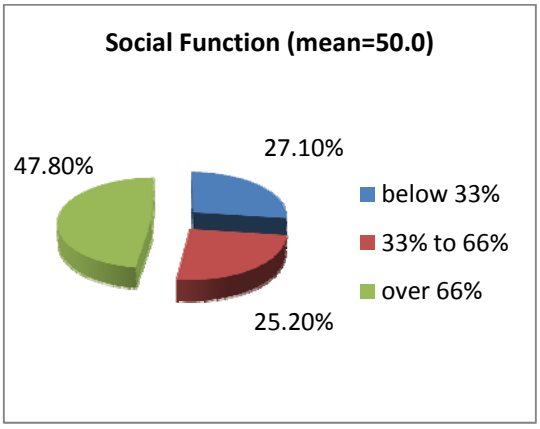

Figure (5.11): 33% cut-off point classification of SF.

In figure (5.11), 47.8% of participants had a good social function (>66%).

5.2.5. Relationship between patients' characteristics and GQoL, QoL domains, and the most significant symptoms and issues; (t-test & ANOVA):

Table (5.10) indicates that there were significant differences at the level (α=0.05) between the means of PF and RF components attributed to **age group** of the participants. Tukey test shows that the differences in PF were between the age group (18-40) and (41-64) and (≥65) in favor of the younger age groups. This indicates that the younger the cancer patients the better **Physical Function** they have. However, Tukey test shows that the differences in RF were between the (≥65) and the age groups (18-40) and (41-64) in favor of younger ages. This means that the younger the participants the better **Role Function** they have.

Table (5.10) indicates that there were significant differences at the level (α=0.05) between the means of GQoL, PF, RF, EF, CF, and SF components attributed to **Educational level** of the participants. Tukey test shows that the differences in GQoL were between the illiterate and secondary/ university levels in favor of the later; and the differences between the primary/ secondary and university in favor of university. This indicates that the higher the educational level the better the **QoL** of the cancer patients. However, Tukey test shows that the differences in PF were between the illiterate and primary/ secondary/ university levels in favor of the later; and the differences between the primary and university in favor of university. This indicates that the higher the educational level the better the **Physical Function** of the cancer patients. Moreover, Tukey test shows that the differences in RF were between the illiterate and secondary/ university levels in favor of the later. This means that patients with secondary and university levels have better **Role Function**. In addition, Tukey test shows that the differences in EF were between the illiterate and secondary/ university levels in favor of the later. This means that patients with secondary and university levels have better **Emotional Function**. Finally, Tukey test shows that the differences in SF were not significant. However, the means show that the higher the educational level the better the **Social Function** of the respondents.

Table (5.10) indicates that there were significant differences at the level (α=0.05) between the means of GQoL, PF and EF components attributed to **monthly income** of the participants. Tukey test shows that the differences in GQoL were between the classes (<2000 NIS) and (2000-4000 NIS) and (>4000 NIS) in favor of the higher income patients.

This indicates that the higher income of the cancer patients the better **QoL** they have. However, Tukey test shows that the differences in PF and EF were between the (>4000 NIS) and the classes (<2000 NIS) and (2000-4000 NIS) in favor of (>4000 NIS) class. This means that the higher income the better **Physical and emotional Function** of the participants.

Table (5.10) indicates that there were significant differences at the level (α=0.05) between the means of PF components attributed to **marital status** of the participants. Tukey test shows that the differences in PF were between the singles and those who are married or other status (widow, divorced) in favor of the single patients. This indicates that the single participants have the better **physical function**.

Table (5.10) indicates that there were significant differences at the level (α=0.05) between the means of GQoL, PF, CF, and SF components attributed to **department of care** of the participants. The differences in GQoL were in favor of the outpatient department, with a higher mean of responses to better **GQoL** for outpatients compared to inpatients. However, the differences in PF, CF, and SF were in favor of outpatients, indicating that outpatients reported better **Physical, cognitive, and social Functions** compared to inpatients.

Table (5.10): Patients **GQoL** and QoL five **domains** according to their socio-demographic characteristics (ANOVA & t-test).

Variables		GQoL			Physical Function			Role Function			Social Function			Cognitive Function			Emotional Function		
		Mean	T / F	P-value	Mean	T / F	P-value	Mean	T / F	P-value	Mean	T / F	P-value	Mean	T / F	P-value	Mean	T / F	P-value
Gender	Male	41.6	-0.1	0.9	48.1	-0.2	0.8	49.0	0.1	1.0	48.3	-0.7	0.5	61.5	0.5	0.6	49.5	1.7	0.1
	Female	41.9			48.8			48.7			51.2			59.8			43.5		
Age group	18- 40	46.4	1.9	0.15	63.3	17.9*	<0.01	61.5	7.2*	<0.01	50.0	0.7	0.47	63.1	1.3	0.27	48.4	1.0	0.38
	41-64	41.8			48.6			49.8			51.7			61.4			46.7		
	>65	37.3			34.5			36.0			45.3			55.1			41.4		
Educational level	illiterate	32.8	7.3*	<0.01	31.5	14.8*	<0.01	34.7	5.0*	<0.01	41.4	1.8*	<0.01	46.9	7.6	0.15	35.6	5.9*	<0.01
	primary	40.4			48.3			47.3			52.9			62.8			44.3		
	secondary	43.5			55.9			55.7			50.5			61.5			51.7		
	university	56.1			63.3			59.6			56.3			74.6			58.1		
Place of residence	city	43.6	0.6	0.56	48.9	0.3	0.75	49.9	0.8	0.46	53.5	1.6	0.20	62.2	1.0	0.35	44.8	0.5	0.58
	village	40.3			47.3			48.9			47.9			59.7			46.6		
	camp	42.3			52.4			36.7			37.2			50.0			38.3		
Monthly income	<2000 NIS	38.1	12.9*	<0.01	46.1	8.6*	<0.01	46.1	2.0	0.14	47.0	2.7	0.07	58.0	1.9	0.14	43.6	6.2*	<0.01
	2000 - 4000	49.3			47.5			51.8			56.2			65.1			47.4		
	>4000 NIS	69.4			79.4			66.7			65.3			69.4			74.3		
person taking care of patient	self caring	45.6	1.3	0.27	59.1	8.6*	<0.01	56.3	2.3	0.07	56.1	1.4	0.23	64.5	1.6	0.19	49.1	1.0	0.40
	family	40.1			41.1			46.9			46.9			60.2			43.3		
	paid persn	25.0			46.7			50.0			50.0			83.3			75.0		
	Both	39.5			45.9			41.7			47.0			55.0			45.5		
Marital status	single	42.8	0.6	0.56	62.0	6.2*	<0.01	60.4	2.2	0.12	57.7	1.0	0.39	63.5	0.6	0.55	46.3	1.0	0.36
	married	42.4			48.0			48.1			48.8			59.4			47.2		
	other	37.6			39.0			42.6			48.6			64.3			39.3		
Living condition	alone	47.0	2.1	0.12	52.2	0.2	0.80	58.7	1.8	0.16	51.3	0.04	0.96	64.0	0.2	0.83	41.3	0.3	0.74
	with family	41.6			48.1			48.3			49.9			60.2			46.5		
	Other	18.8			46.7			20.8			45.8			58.3			45.8		

Table (5.10 a): Patients **GQoL** and QoL five **domains** according to their socio-demographic characteristics (ANOVA & t-test).

Variables		GQoL			Physical Function			Role Function			Social Function			Cognitive Function			Emotional Function		
		Mean	T / F	P-value	Mean	T / F	P-value	Mean	T / F	P-value	Mean	T / F	P-value	Mean	T / F	P-value	Mean	T / F	P-value
House ownership	rented	32.4	-1.9	0.1	42.5	-1.1	0.3	34.6	-2.0	0.1	37.8	-1.7	0.1	61.5	0.2	0.9	37.3	-1.5	0.1
	owned	42.6			49.0			50.1			51.1			60.4			46.8		
Place of treatment	Bet Jala H	39.3	2.5	0.08	46.6	2.0	0.14	47.3	1.2	0.30	48.1	0.8	0.47	59.0	0.6	0.54	43.7	1.6	0.21
	Watani H	48.1			45.6			42.7			55.8			62.7			47.4		
	AVH	45.3			53.5			53.7			52.3			63.0			50.6		
Department of care	Outpatient	44.6	3.3*	<0.01	52.3	4.0*	<0.01	51.2	1.7	0.084	52.9	2.3*	<0.05	63.5	3.0*	<0.01	47.1	1.0	0.312
	In-patient	33.8			38.2			42.2			42.1			51.9			43.1		
Stage of disease	stage 1	55.2	14.1*	<0.01	71.7	25.8*	<0.01	87.5	14.0*	<0.01	64.6	8.6*	<0.01	75.0	10.5*	<0.01	55.2	18.3*	<0.01
	stage 2	57.5			67.5			68.3			68.5			74.3			67.3		
	stage 3	41.4			51.5			47.2			48.8			61.0			44.6		
	stage 4	31.0			32.0			32.9			38.2			48.3			32.2		
	Unknown	34.7			36.7			77.8			41.7			83.3			70.0		
Time span of treatment	< 3 month	48.2	5.1*	0.01	56.4	5.6*	<0.01	54.0	2.5	0.08	56.3	2.3	0.11	59.9	1.1	0.33	51.8	2.0	0.13
	3 - 6 mon	46.5			54.0			56.5			54.7			66.0			47.9		
	> 6 month	38.0			44.4			45.1			46.6			59.0			43.3		
Region	Northern	47.8	5.7*	<0.01	47.9	5.9*	<0.01	47.0	1.7	0.18	51.4	6.6*	<0.01	60.5	4.0*	0.02	48.1	3.3*	0.04
	Middle	48.0			59.1			57.0			64.8			70.4			53.2		
	Southern	37.8			44.3			46.2			44.6			57.1			41.8		

Table (5.10) indicates that there were significant differences at the level (α=0.05) between the means of GQoL, PF, RF, EF, CF, and SF components attributed to **stage of disease** of the participants. Tukey test shows that the differences in GQoL were between stages (4) and stages (2 & 3) in favor of the later. This indicates that the earlier the stage the better the **QoL** of the participants. However, Tukey test shows that the differences in PF were between stage (4) and stages (1&2&3) in favor of the later; and the differences between (2) and (3) in favor of stage (2). This indicates that the earlier the stage the better the **Physical Function** of the participants. Moreover, Tukey test shows that the differences in RF were between stage (4) and stages (1&2&3) in favor of the later; and the differences between stage (3) and stages (1&2&4) in favor of stages (1 &2) as they have the higher means. This means that participants with stages (1&2) have better **Role Function** than stages (3 &4). In addition, Tukey test shows that the differences in EF and CF were between stage (4) and stages (2&3) in favor of the later; and the differences between stage (3) and (2) in favor of stage (2). This means that participants with earlier stages have better **Emotional and cognitive Functions**. Finally, Tukey test shows that the differences in SF were between stages (2) and stages (3&4) in favor of stage (2). This means that participants with stage (2) have better **Social Function**.

Table (5.10) indicates that there were significant differences at the level (α=0.05) between the means of GQoL and PF components attributed to **duration of treatment** of the participants. Tukey test shows that the differences in GQoL and PF were between the duration of less than 3 months and more than 6 months in favor of the later. This indicates that the longer the duration of treatment the worse the **QoL and physical function** of the participants.

Table (5.10) indicates that there were significant differences at the level (α=0.05) between the means of GQoL, PF, RF, EF, CF, and SF components attributed to **region of living** of the participants. Tukey test shows that the differences in GQoL were between the southern and both northern and middle regions in favor of the later. This indicates that there is lower level of **QoL** of the participants who are living in the southern region of the West Bank of Palestine. However, Tukey test shows that the differences in PF, CF, and SF were between the south and middle in favor of the middle. This means that **Physical, cognitive, and social Functions** of the participants are worse/ lower in those living in the southern region of the West Bank.

The following items are found statistically non-significant for comparison of means upon testing with t-test and ANOVA with GQoL, PF, RF, SF, CF, EF; those factors are gender, Place of residence, Living condition, House ownership, Place of treatment, and the Type of treatment.

Table (5.11): Patients' **FA**, **FI**, and **PA** according to their socio-demographic characteristics (ANOVA &t-test).

Variables		FA			FI			PA		
		Mean	T / F	P-value	Mean	T / F	P-value	Mean	T / F	P-value
Gender	Male	64.6	-1.0	0.3	66.9	1.0	0.3	62.9	0.05	1.0
	Female	68.0			62.9			63.0		
Age group	<18-40	59.5	5.5*	<0.01	61.0	0.4	0.64	58.3	2.0	0.14
	41-64	65.8			65.9			62.2		
	>65	75.8			66.2			69.9		
Educational level	illiterate	82.0	14.5*	<0.01	74.5	4.6*	<0.01	78.1	9.3*	<0.01
	primary	68.4			65.2			63.3		
	Secondary	60.7			62.7			58.3		
	University	48.6			48.0			43.7		
Place of residence	city	68.1	0.4	0.70	58.5	2.9	0.06	61.3	0.8	0.47
	village	65.7			68.0			63.9		
	camp	70.6			73.3			72.2		
Monthly income	< 2000 NIS	69.8	10.4*	<0.01	71.0	20.7*	<0.01	65.5	6.9*	<0.01
	2000 - 4000	64.2			49.0			60.3		
	> 4000 NIS	33.3			19.4			29.2		
person taking care of patient	self caring	60.8	3.3*	0.02	62.3	0.7	0.57	57.6	1.4	0.23
	family memb	70.6			64.1			66.3		
	paid person	22.2			100.0			50.0		
	Both (1&2)	68.4			67.9			65.6		
Marital status	single	61.9	0.8	0.44	50.0	4.0*	0.02	54.4	1.4	0.24
	married	66.5			66.0			64.5		
	other	70.6			72.1			62.2		
Living condition	living alone	65.3	1.3	0.29	64.0	1.1	0.33	60.4	0.8	0.46
	with family	66.4			64.1			62.8		
	other	88.9			91.7			83.3		
House ownership	rented house	72.0	1.0	0.3	79.5	2.2*	0.01	73.7	1.7	0.1
	owned house	66.1			63.2			62.0		
Place of treatment	Beit Jala H.	68.7	1.5	0.24	65.3	0.3	0.71	65.6	2.0	0.13
	Watani H.	61.8			59.0			52.7		
	AVH	63.4			64.6			60.1		
Department of care	Outpatient	63.2	-3.5*	0.001	62.1	-2.0*	0.046	58.4	-4.2*	0.001
	In-patient	75.8			71.4			75.5		
Stage of disease	stage 1	54.2	25.1*	<0.01	41.7	5.1*	<0.01	47.9	19.4*	<0.01
	stage 2	45.8			53.2			39.3		
	stage 3	66.5			62.5			62.7		
	stage 4	82.5			74.8			80.2		
	Unknown	51.9			72.2			61.1		
Time span of treatment	< 3 months	62.3	3.5*	0.03	59.7	2.4	0.09	58.3	1.9	0.15
	3 - 6 months	60.3			57.9			57.7		
	> 6 months	70.0			68.2			65.9		
Region	Northern	65.0	3.1	0.05*	66.7	3.2	0.04*	58.3	2.0	0.14
	Middle	59.3			53.9			58.2		
	Southern	69.9			67.8			66.4		

Table (5.11) indicates that there were significant differences at the level (α=0.05) between the means of FA components attributed to **age group** of the participants. Tukey test shows that the differences in FA were between the age group (>65) and the age groups (18-40) and (41-64) in favor of older ages. This means that the older the cancer patients in this study the more **Fatigue** they have. However, pain and financial difficulties did not reach the statistical significance, but the means show more pain and more financial difficulties as the patients are more advancing in age.

Table (5.11) indicates that there were significant differences at the level (α=0.05) between the means of FA, PA, and FI components attributed to **educational level** of the participants. Tukey test shows that the differences in FA were between the illiterate and primary, secondary, and university levels in favor of the illiterate; and the differences between the primary and university in favor of primary. This indicates that the higher the educational level of the respondents the less the **Fatigue**. However, Tukey test shows that the differences in PA were between the illiterate and primary, secondary, and university levels in favor of the illiterate; and the differences between the primary and university in favor of primary. This indicates that the higher the educational level of the participants the less the **Pain** they suffer. In addition, Tukey test shows that the differences in FI were between the illiterate and primary with university level in favor of the formers. This means that the participants with university degree have less **financial difficulties**.

Table (5.11) indicates that there were significant differences at the level (α=0.05) between the means of FA, PA and FI components attributed to **monthly income** of the participants. Tukey test shows that the differences in FI were between the classes (<2000 NIS) and (2000-4000 NIS) and (>4000 NIS) in favor of the less income patients. This indicates that the less income the respondents the more **financial difficulties** they have. However, Tukey test shows that the differences in FA and PA were between the (>4000 NIS) and the classes (<2000 NIS) and (2000-4000 NIS) in favor of the less income classes. This means that the less income the more **Fatigue and pain symptoms distress** the respondents.

Table (5.11) indicates that there were significant differences at the level (α=0.05) between the means of FI components attributed to **marital status** of the participants. Tukey test shows that the differences in FI were between the singles and those who are married or other status (widow, divorced) in favor of the other status patients. This means that the widow and divorced participants have more **financial difficulties**.

Table (5.11) indicates that there were significant differences at the level (α=0.05) between the means of FI components attributed to **House ownership** of the participants. The differences in FI were in favor of the rented houses, with a higher mean of responses to more **financial difficulties** for rented houses compared to owned houses ownership.

Table (5.11) indicates that there were significant differences at the level (α=0.05) between the means of FA, FI, and PA components attributed to **department of care** of the participants. The differences in FA, FI, and PA were in favor of the inpatient department, with a higher mean of responses to more intense symptoms and issues **(fatigue, pain, financial difficulties)** for inpatients compared to outpatients.

Table (5.11) indicates that there were significant differences at the level (α=0.05) between the means of FA, FI, and PA components attributed to **stage of disease** of the participants. Tukey test shows that the differences in FA and PA were between stage (4) and stages (1&2&3) in favor of stage (4) which has a higher mean; and the differences between (2) and (3) in favor of stage (3). This indicates that the later the stage the worse the **fatigue and pain** of the cancer patients. However, Tukey test shows that the differences in FI were between stage (4) and stage (2) in favor of (4). This indicates that the later the stage the more the **financial difficulties** for the participants.

Table (5.11) indicates that there were significant differences at the level (α=0.05) between the means of FA components attributed to **duration of treatment** of the participants. Tukey test shows that the differences in FA were in favor of the longer duration. This means that the longer the duration of treatment the more the **fatigue** of the participants.

Table (5.11) indicates that there were significant differences at the level (α=0.05) between the means of FA and FI components attributed to **region** of the participants. Tukey test shows that the differences in FA and FI were between the middle and southern region in favor of the southern. This means that the participants who are living in the southern region of the West Bank of Palestine have the more **fatigue symptoms and financial difficulties**.

The following items are found to be statistically non-significant for comparison of means upon testing with t-test and ANOVA for FA, FI, and PA; these factors are gender, Place of residence, Living condition, Place of treatment, and the Type of treatment.

According to the region of the West Bank of Palestine, figure (5.12) presents poorer GQoL, EF, PF, SF, and CF, and more intense symptom and financial difficulties in the southern region in comparison with the middle or the northern regions.

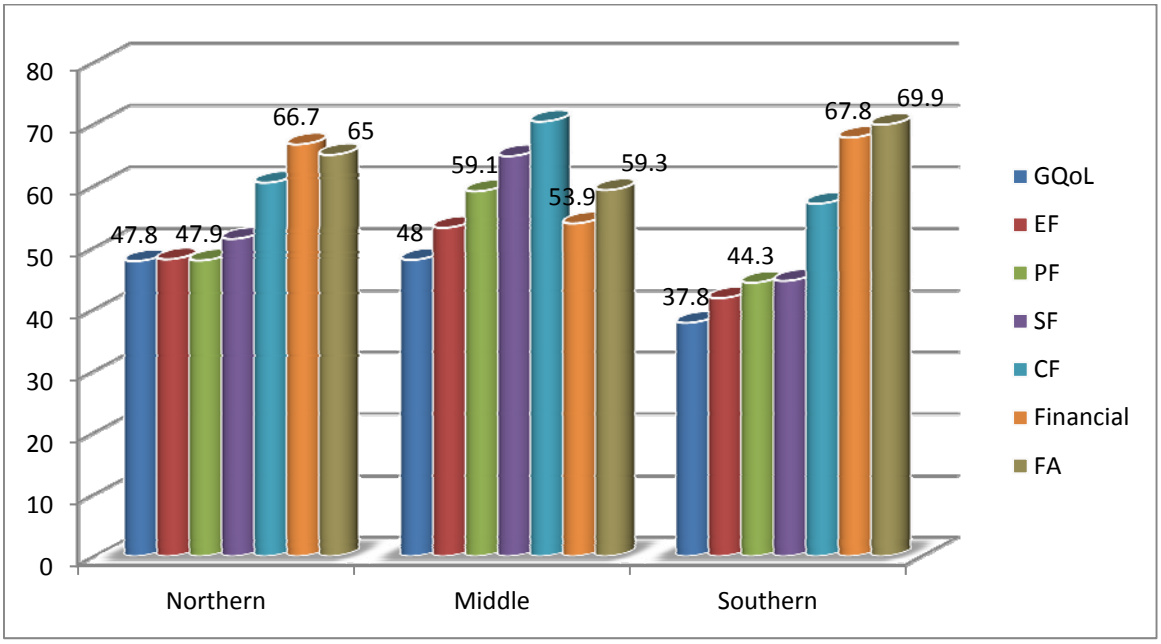

Figure (5.12): Statistically significant ($p<0.05$) variables (Means for GQoL and other domains) according to region.

5.2.6. The relationship between GQoL and symptoms associated with cancer (Pearson's correlation):

The results show that there is a significant negative/ inverse relationship at the level ($\alpha=0.05$) between the GQoL and symptoms associated with cancer and financial difficulties. These relationships were strongest with pain ($r = -0.622$, $p< 0.001$), fatigue ($r = -0.620$, $p< 0.001$), insomnia ($r = -0.447$, $p< 0.001$), dyspnea ($r = -0.423$, $p< 0.001$), and financial difficulties ($r = -0.393$, $p< 0.001$) as shown in table (5.12). Further details available in Annex (1).

Table (5.12): Significant relationships between **GQoL** and cancer symptoms and financial difficulties (Pearson's correlation).

	FA	N&V	Pain	DY	SL	AP	CO	DI	FI
R	-0.62	-0.39	-0.62	-0.423	-0.447	-0.39	-0.33	-0.224	-0.39
p-value	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01

5.2.7. The relationship between stage of cancer and independent variables:

In cross tabulation between cancer stage and other independent variables, significant relationship with the educational level was found as shown in figure (5.13). It is clear that low educated respondents had more advanced stages of cancer (stage III and IV); 88.7% of illiterates have advanced stage cancer, while 57.5% only in the university level.

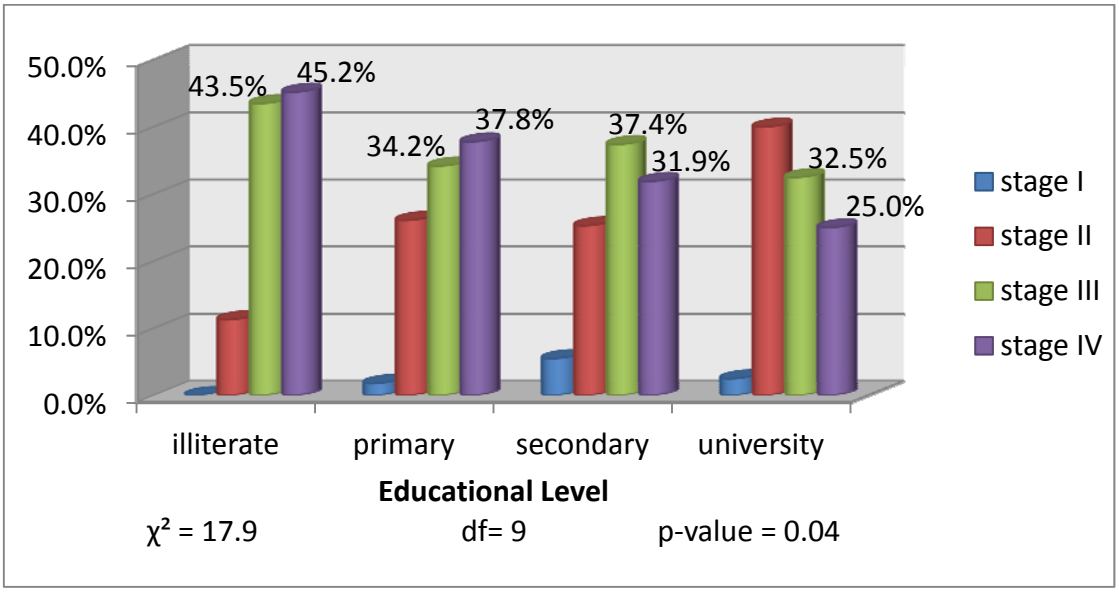

Figure (5.13): The relationship between **stage (1-4)** of cancer and **educational** level of respondents; Cross tabulation (Chi square test (χ^2)

5.2.8. Predictors of GQoL and QoL domains; (Regression analysis):

In the regression model we included all variables that were significant according to P value in the bivariate analysis ($P < 0.05$), and we presented only those that were still significant in the regression analysis.

According to table (5.13) there is significant relationship at the level ($\alpha=0.05$) between the GQoL and educational level, monthly income, stage of cancer, and duration of treatment for cancer.

Table (5.13): Regression analysis: significant relationship between **GQoL** and independent variables.

Independent variables	F-value (ANOVA)	P-value	β-Value (Regression)	P-value
Education of patient	7.3	<0.01	0.118	0.041
Monthly income	12.9	<0.01	0.186	0.001
Stage of disease	14.1	<0.01	-0.304	<0.001
Time span of treatment	5.1	=0.01	-0.108	0.042

R square (R^2) = 0.251

The strongest predictor of GQoL was the stage of cancer with a negative relationship; as the increase in stage means worse GQoL, then the monthly income with a positive relationship, then the educational level with a positive relationship, then finally the duration of cancer treatment with a negative relationship (figure 5.14). The coefficient of determination (R^2) shows that 25.1% of the variance of the GQoL explained by the independent variables shown in table (5.13).

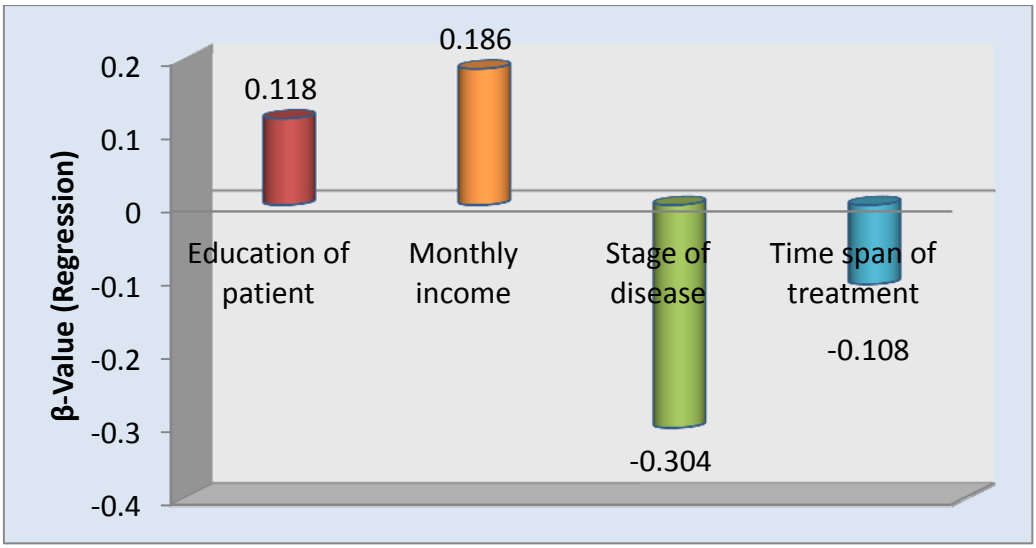

Figure (5.14): Predictors of GQoL according to regression analysis of significant variables (P <0.05).

According to table (5.14) there is a significant relationship at the level (α=0.05) between the PF and educational level, person taking care of the patient, department of treatment (outpatient or inpatient), stage of cancer, age, and duration of treatment for cancer.

Table (5.14): Regression analysis: significant relationship between **Physical function** and the independent variables.

Independent variables	F-value (ANOVA)	P-value	β-Value (Regression)	P-value
Education of patient	14.8	<0.01	0.18	0.002
Department of care (t-value)	4.0	<0.01	-0.21	<0.001
Stage of disease	25.8	<0.01	-0.37	<0.001
Time span of treatment	5.6	<0.01	-0.10	0.043
Age Group	17.9	<0.01	-0.19	0.001

R square (R^2) = 0.406

The strongest predictor of PF was the stage of cancer with a negative relationship, then the department with worse effect on PF for inpatients, then the age with a negative effect, then

the educational level with a positive relationship, then finally the duration of cancer treatment with a negative relationship. The coefficient of determination (R^2) shows that 40.6% of the variance of the PF explained by the independent variables shown in table (5.14).

According to table (5.15) there is a significant relationship at the level (α=0.05) between the RF and the stage of cancer.

Table (5.15): Regression analysis: significant relationship between **Role function** and stage of disease.

Independent variables	F-value (ANOVA)	P-value	β-Value (Regression)	P-value
Stage of disease	14.0	<0.01	-0.31	<0.001

R square (R^2) = 0.154

The strongest predictor of RF was the stage of cancer with a negative relationship. The coefficient of determination (R^2) shows that 15.4% of the variance of the RF explained by the stage of cancer as shown in table (5.15).

According to table (5.16) there is a significant relationship at the level (α=0.05) between the SF and the stage of cancer.

Table (5.16): Regression analysis: significant relationship between **Social function** and the stage of disease.

Independent variables	F-value (ANOVA)	P-value	β-Value (Regression)	P-value
Stage of disease	8.6	<0.01	-0.27	<0.001

R square (R^2) = 0.098

The strongest predictor of SF was the stage of cancer with a negative relationship. The coefficient of determination (R^2) shows that 9.8% of the variance of the SF explained by the stage as shown in table (5.16).

According to table (5.17) that there is significant relationship at the level (α=0.05) between the CF and the variables of department of treatment (outpatient or inpatient), and stage of cancer.

Table (5.17): Regression analysis: significant relationship between **Cognitive function** and the independent variables.

Independent variables	F-value (ANOVA)	P-value	β-Value (Regression)	P-value
Stage of disease	10.5	<0.01	-0.26	<0.001
Department of care (t-value)	3.0	<0.01	-0.14	0.015

R square (R^2) = 0.097

The strongest predictor of CF was the stage of cancer with a negative relationship, then the department with worse effect on CF for inpatients. The coefficient of determination (R^2) shows that 9.7% of the variance of the CF explained by the independent variables shown in table (5.17).

According to table (5.18) there is a significant relationship at the level (α=0.05) between the EF and the variables of educational level, and stage of cancer.

Table (5.18): Regression analysis: significant relationship between **Emotional function** and the independent variables.

Independent variables	F-value (ANOVA)	P-value	β-Value (Regression)	P-value
Stage of disease	18.3	<0.01	-0.35	<0.001
Education of patient	5.9	<0.01	0.15	0.012

R square (R^2) = 0.182

The strongest predictor of EF was the stage of cancer with a negative relationship, then the educational level with a positive relationship. The coefficient of determination (R^2) shows that 18.2% of the variance of the EF explained by the independent variables shown in table (5.18).

According to table (5.19) there is a significant relationship at the level (α=0.05) between the FA and the variables of educational level, department of treatment (outpatient or inpatient), stage of cancer.

Table (5.19): Regression analysis: significant relationship between **Fatigue** and the independent variables.

Independent variables	F-value (ANOVA)	P-value	β-Value (Regression)	P-value
Stage of disease	25.1	<0.01	0.32	< 0.001
Education of patient	14.5	<0.01	-0.22	< 0.001
Department of care	3.5	<0.01	0.15	0.004

R square (R^2) = 0.278

The strongest predictor of FA was the stage of cancer with a positive relationship, then the educational level with a negative relationship, then the department with worse effect on FA for inpatients. The coefficient of determination (R^2) shows that 27.8% of the variance of the FA explained by the independent variables shown in table (5.19).

According to table (5.20) there is a significant relationship at the level (α=0.05) between the FI and the variables of stage of cancer, and monthly income.

Table (5.20): Regression analysis: significant relationship between **Financial difficulties** and the independent variables.

Independent variables	F-value (ANOVA)	P-value	β-Value (Regression)	P-value
Stage of disease	5.1	<0.01	0.17	0.002
Monthly income	20.7	<0.01	-0.31	< 0.001

R square (R^2) = 0.180

The strongest predictor of FI was the monthly income of the cancer patient with a negative relationship indicating more financial difficulties with less income, then the cancer stage with a positive relationship indicating more financial difficulties with advanced stages of cancer. The coefficient of determination (R^2) shows that 18% of the variance of the FI explained by the independent variables shown in table (5.20).

According to table (5.21) there is significant relationship at the level (α=0.05) between the PA and the variables of educational level, department of treatment (outpatient or inpatient), and stage of cancer.

Table (5.21): Regression analysis: significant relationship between **Pain** and the independent variables.

Independent variables	F-value (ANOVA)	P-value	β-Value (Regression)	P-value
Education of patient	9.3	<0.01	-0.208	<0.001
Department of care (t-value)	-4.2	<0.01	0.176	0.001
Stage of disease	19.4	<0.01	0.359	<0.001

R square (R^2) = 0.266

The strongest predictor of PA was the stage of cancer with a positive relationship indicating more severe pain in advanced cancer stages, then the educational level with a negative relationship indicating less pain for highly educated patients, then the department (outpatient or inpatient) with worse effect on PA for inpatients. The coefficient of

determination (R^2) shows that 26.6% of the variance of the PA explained by the independent variables shown in table (5.21).

5.3 Qualitative Results

5.3.1. Demographic characteristics of the qualitative sample:

The qualitative part consists of 10 in-depth-interviews that were conducted with cancer patients from different areas of the West Bank of Palestine. Also, those patients were from different ages, genders, backgrounds, and diagnoses. Table (5.22) shows the characteristics of informants.

The cases were from most areas of the West Bank; Hebron, Bethlehem, Jenin, Ramallah, and Nablus. The participants' age ranged from 25 to 70 years old and 6 females and 4 males. The diagnoses were breast cancer, lymphoma, uterine cancer, leukemia, colon cancer, brain cancer, and lung cancer.

Table (5.22): Characteristics of respondents.

Sex	**Age**	**Area**	**Diagnosis**
Female	50	Hebron	Breast Ca
Female	25	Bethlehem	Lymphoma
Female	42	Jenin	Uterine Ca
Male	60	Hebron	Leukemia
Male	46	Ramallah	Colon Ca
Male	70	Hebron	Colon Ca
Female	41	Hebron	Breast Ca
Female	34	Nablus	Brain Ca
Female	46	Ramallah	Breast Ca
Male	60	Hebron	Lung Ca

5.3.2. Thematic Analysis:

Through the thematic analysis of the in-depth-interviews in this study, seven categories were identified. The categories were originated from the main questions of the interviews and based on the participants' responses. These categories were; (a) Effects of cancer on the daily life, (b) Personal perceptions of cancer, (c) Factors affecting coping status with cancer, (d) Patients' beliefs regarding treatment, (e) Barriers to service delivery, (f) Satisfaction of patients with service delivery, and (g) Community perceptions for cancer and cancer patients. Moreover, patients' needs were identified and discussed in terms of QoL.

For each category, several themes were indentified. Annex (2) illustrates and categorizes all these data, as well as, provides the supporting original text in Arabic as the patients had said literally. Also, the table provides English translation of the most important quotations of participants' responses that are included in the body of the text in this study.

1. Effects of cancer on the daily life.

The effects of cancer on the daily life of patients were classified into five themes; physical, social, psychological, sexual, and financial. The **physical effects** were apparent mainly through pain and fatigue from the disease process and chemotherapy treatment, besides some other physical symptoms like edema and bleeding. A female breast cancer patient from Hebron governorate who aged 50 years said;

> "All my strength collapses; I didn't have the power to stand to drink water. The pain is the worst; even it is worse than cancer itself"

Another female patient from Nablus governorate (34 years) with brain cancer said;

> "I have a lot of fatigue; I feel tired when I take the chemotherapy, sometimes I fall unconscious when I am at the hospital, also, there is pain in my back… I can't take it anymore, all the times I am in the bed"

Role performance were concentrated around issues like the relationships among the family and the family feelings toward each others, roles and duties of family members, and resulted fear, anxiety, stress and burden of having a cancer patient in the family. A breast cancer female patient from the south area said;

> "The most important thing to me is to be with my kids; their feelings were abnormal, I was away outside home, I was taking hypnotic and sleep for hours, they were lost in that time."

Sexuality: it was through the expression of frigidity and cold feelings among spouses, expression of low desire and unwillingness for a relationship, feeling of fatigue, and even refusal of continuing the marriage in some cases. A breast cancer patient of 41 years old said;

> "After chemotherapy, I feel tired when I am back at home. Off course, this cause indolence and frigidity at home… whatever, it has an effect."

Another patient said;

> "I have no desire, I don't think about it, actually nothing is between us now. Actually I asked for divorce before I had my surgery."

Psychologically, the effects were illustrated in fear due to unawareness and poor understanding of the disease process and treatment consequences, death ideation, denial, hopelessness, sadness, coupled to disease and hospital, troubling feelings, and negative impact of the disease in life aspects. A male colon cancer patient from the south who is 70 years old said;

> "They told me you are in need for urgent surgery; I was terrified… how they are going to open my abdomen!? So, I ran away for six months, then I was really tired, so, I said do it and open my abdomen… if I'll die, let me die."

This example showed that physician does not give enough explanation for the patients and patients are unaware of their rights toward their role in the treatment plan that depends on real understanding of their health problem. Such lack of knowledge may lead to anxiety and fear among patients. it seems that patients do not have the courage to ask questions because they believe that their treatment is physician's decision. In addition, they fear that asking questions may upset the physicians and this affects their treatment.

2. Personal perceptions of cancer.

Patients' perceptions of their disease status, causes, and consequences were classified into self integration with the disease, **shame feeling** from being a cancer patient, and **feeling of guilt** from being diseased. A 25 years female with lymphoma said;

> "Indeed, I am the only one with cancer in my area of living."

Their ideations, beliefs, and understanding for their disease were that cancer is death, **fear** from discovering that they have the disease, incurability of cancer, and no necessity for pain management as it causes addiction. Death anxiety was clear through a 42 years old patient with uterine cancer from Jenin said;

> "I think I am going to die and that's it, this disease means death and I am already going to die… actually, all those with this disease are died."

Also, they link cancer causes with other treatments they had taken, with the Israeli nuclear weapon, with chemical factories, food preservatives and fruits & vegetables fertilizers, with smoking, or contagion. One participant said;

> "I don't think there is complete cure for cancer… I think my disease was caused by hormonal therapy for infertility, or some people are saying it is the nuclear weapon of Israel and its factories in Dimona."

And sometimes, they are considering it as ordeal, test or mercy from God, or sometimes, as **punishment** for doing sins or expiation to remove these sins. Spirituality was clear through what a leukemia patient from Hebron area speech;

> "The disease cause is from God, it is not shame or demerit, it is mercy; our God is testing us by the disease, it is mercy and expiation of sins."

They believed also, that **acceptance** of the disease and its pain is a must and no need to take actions against it, as cure is something beyond capabilities of human beings, or sometimes it depends on their spirit and morale. A patient from the north said;

> "I am feeling that I'll be taking treatment for all my life; indeed I am not aware of the cause of this disease."

3. Factors affecting coping status with cancer.

Through analysis of the cancer patients' responses, several factors were illustrated that might have effect on the patients' acceptance of the cancer, and in enhancing their ability to cope. These factors were having **commitment toward others** and having goal in life, personality, attitudes, knowledge, and having faith and religious beliefs which had an apparent effect on patients through enforcing their abilities and strengthening their spirituality, also, having a support system from social and familial context or from the

treating professionals. Role performance was apparent in a female patient from Bethlehem who said while describing her commitment toward her family;

> "The woman lives in this life mostly for her kids; especially that mine are girls."

Personal factors that helped patients to overcome the struggle of having cancer in many times were illustrated in having better ability to fight against troubles in life due to experience with the disease, having own house and privacy, having patience and ability to tolerate, having own competence, and having knowledge about their condition. A 46 years old patient with breast cancer from Ramallah said describing her ability to cope with the disease;

> "What helped me was that I know what my disease is, and I believe it is easier than other types… thank God, I am patient and accepting my condition… may God cure us by Doaa (supplication)."

Faith and religious beliefs (spirituality) of patients were clearly apparent in supporting them and providing them with strength and power to stand in front of such disease. Their rationales of faith in front of disease were that cure is only from God. The need for strong faith in such condition through praying and reading Quran, obedience of God will and destiny, acceptance of death as being with the hands of God and that death is the final end anyway, "Tawakul" or trust in God that he is taking care of human, faith that disease is mercy from God to expiate sins and not a punishment, and the Islamic directives of combining the best possible treatment with full faith and supplication to God. A lung cancer patient who is 60 years old said while explaining his way of dealing with cancer and how he is coping with the disease;

> "Faith in Allah (God) helped me through; he is the cause and the cure of the disease… firstly, we are in the hands of God; he is "AL-Shafi" the healer… and the person needs to accept it, needs to be faithful in God… for me, this is before everything, even before treatment."

The support system was another factor which helped patients to overcome and cope with cancer. The support that the patients have is mainly from their families and social context, and in some cases there was some support and education from the health care providers. A patient said in her answer toward the inquiry about support from the health team;

> "The nurse is the one who was helping us, he is the one who is giving us the treatment and he is the one who is providing advices and education."

Moreover, patients expressed their satisfaction with all types of help and support from anyone in the community, and they stressed on the psychological and emotional effects of that type of support for overcoming the crises of cancer, especially in the absence of any other specialized or **professional support system**. In that context a 42 years old cancer patient from Jenin said;

> "All of them helped me… my husband, my relatives, and the neighbors... thank God, but the help of my husband was the most. They were all with me on the day of my surgery, which really made me relaxed; I went into the surgery calm and reassured as they were around me… off course; the family provides help, thanks God."

Another patient who is 70 years old and has colon cancer said;

> "I swear by God that nothing helped me at all, no body except of my children who helped me."

4. Patients' beliefs regarding treatment.

Patients' beliefs and understanding regarding their treatment for cancer were classified into two parts; toward curative medicine and toward other integrative modalities of medicine. Informants' attitudes were either **positive or negative** towards these treatments according to their experiences. A patient from the south said;

> "last thing, I had severe pain in my abdomen and in my back, maybe due to the large amount of medication which I am taking; as any medication may affect the liver, and I am trying to avoid such thing and take care… maybe I should bear the pain better than bearing the medication side effects."

Another patient from the north said;

> "They told me take Anise, Chamomile, and other herbs… with no benefit, no benefit at all."

5. Barriers to service delivery.

The barriers were classified into economical, political, and policy and regulation. The **economic barriers** were treatment related expenses such as costs of transportation, and food and accommodation for the companion, which are usually not easy for them to handle. Therefore, there is need for policy and regulations that enable easy access to treatment centers and accommodation facilities that would decrease patients suffering. This was expressed by one patient while explaining her problem;

> "The transportations are not covered by the insurance, as well as accommodation and food. I hope if they can provide bus to take us to hospital, I am not satisfied with the distance I travel, it is hard for me. I hope there is nearer chemotherapy treatment for us in Hebron."

The **political barriers** are related to difficulty in accessing hospitals for treatment because of check points and need for permits to enter East Jerusalem. Moreover, travelling for long distance from north to south. A 34 years old patient from Nablus area explained her struggle with access to care to East Jerusalem hospitals as follows;

> "And the way to hospital has many, many difficulties… on the metal rotating barriers and at the checkpoints… too much. I have to change my address to AL-Ram because it is easier for me to do the permit paper there. My brothers are all young men, and they were abundant and forbidden from passing the wall checkpoint. I was in Augusta Victoria and Makkasid hospitals… everybody has his relatives around him, and I was setting alone in my bed like a

monkey… I swear by God, I was feeling strangled, I hoped there is anyone of my brothers there… of my family… that would be of great help."

6. Satisfaction of patients with service delivery.

Patients' satisfaction is one of the important themes derived from their responses to open ended questions. Those classified as with healthcare personnel, medical equipments, supplies, services, and referral system.

Some respondents were dissatisfied with **healthcare personnel**, medical treatment plan, pain management, assessment routine, diagnostic testing, and alternative remedies. A lymphoma patient from the south said;

"The doctor said to me not to take medications for the chemotherapy treatment, but only Paracetamol, they told me to take that for pain, indeed, it did not work, it was good in decreasing headache… I was immobile and struggling with pain for days."

Another patient from the north said;

"There is medication for pain… or maybe there is not… I don't know. When I have pain, they told me you will get used to it with time and the pain will fade… I think they were not telling the truth."

On the other hand, some respondents expressed their satisfaction with the health care providers and their hard efforts to meet the high need and load of patients with their limited numbers and capacities. A 60 years old patient from Hebron said;

"I have good trust in the team, they are good… excellent, the nurse here is extra excellent."

There was also "**service provider induced demand**" in some cases. This was through guiding patients to use some healthcare services instead of others; even it was sometimes costly and difficult to reach for patients. A 41 years old female patient with breast cancer told her story when she had mastectomy surgery;

> "We have insurance, but first action we had gone to a private doctor who referred us to a private hospital. This is not good from the doctor… he knew that we have insurance, and we are poor, and the surgery costs a lot. He was supposed to refer us to the governmental hospital, they can do the surgery not less competently, he should refer us… but he didn't. We did pay a lot of money to the private hospital."

Moreover, some respondents were not satisfied with **psychosocial support** and **communication** of healthcare professionals. Mainly, in communicating bad news to patient and family, and dealing with them in anger and toughness, not helping or supporting them, hiding the truth about the disease, unavailability of care and support over the phone, unethical attitude toward patients, and not enough or missing explanation and education. One of the respondents said;

> "The doctor informed me in coldly lethal nerves, as if telling me you have flu: you have a malignant cancer in your brain… I fainted on the spot; I was on the ground unconscious. When I was awake again … he informed me it needs operation and surgical resection… again, and as the first time. That made me mad… two times, I was informed in the same way, as telling a story."

On the other hand, some patients were satisfied with staff communication, sharing in decision making about their disease and treatment plans, providing advices and instructions, and availability of support over the phone.

> "The doctor informed me that it is a small lump, and you have to decide with your family… imagine, I was born again, I took my decision. This is a human being, he treated me as human being… indeed, I am no-more sick after that."

Other source of dissatisfaction was with health **education and awareness** provided to patients and their families. This included insufficient teaching and explanation, absence of educational and awareness material and brochures, and inadequate instructions to deal with the disease symptoms and side effects. A patient of 41 years old said;

> "Indeed, all respect is due to my nurse, more than anybody else. That is because the physician wrote the order only, but the nurse gave us the advices, for all patients, not only me, but for all … may God will reward him the best remuneration ever."

A second theme was related to **medical equipments**, supplies, and services. This included dissatisfaction with quality and scarcity of some diagnostic testing and examination at the governmental health system. A 46 colon cancer patient from middle said;

> "There are some tests available in the government, but others are available outside, not all tests are available."

Also it was mentioned by some respondents the unavailability of medicine and symptom management medications sometimes as a source of discomfort. A leukemia patient of 60 years from the south said;

> "The essential medications are available here, but the other medications; we need to buy it sometimes from outside pharmacies. The treatment is OK; sometimes there are some shortages, but not all the times."

Moreover, some respondents were unhappy with **poor environment**, hygiene, cleanness, crowdedness, lack of privacy, and small space for clinical care. A 25 years old patient who had lymphoma said;

> "The patients are crowded over each others, there is no privacy. The governmental hospital needs to enlarge the areas, so to comfort the patients, it is better for their self-esteem and psychology… indeed, when I came to the hospital I get sicker."

Third theme that was derived from the **referral system**, coverage of medications and procedures include shortage in medications, long waiting lists, complicated referral process, and favoritism. One patient said;

> "I had surgery in private hospital and paid for it, because it was not available at the governmental hospital. I have health insurance, but they kept delaying my surgery… and the doctor advised me not to delay my surgery more, he said: it is not good for you. So, I had it in private hospital."

7. Community perceptions of cancer patients.

This included pity feelings with cancer patients, **stigmatization** of having cancer, perceiving it as fatal and serious disease, considering it as punishment from God, and sometimes solidarity and help.

Example is perception of patient as dying person. One patient said;

> "The way people look to me is painful; they have pity and sympathy with that poor patient. This is too bad, it affects my psychology. Our community does not accept it, they usually say may God heal you and preserve you for your kids… they let you feel it is the end of your life."

Another example of stigmatization is what a breast cancer patient said;

> "My mother-in-law wanted to marry her son to another wife… also, people tried not to inform me that other cancer patients already died. Also it is hurting when people say cancer is a hereditary disease, this stigmatizes my daughters."

Also, a male leukemia patient said;

> "It is terrifying disease, people perceive it as dangerous… they are usually asking about the cancer patient… how is he? Did he die? Is he still alive?"

Another example for punishment is the opinion of a 41 years old female patient;

> "People think that cancer patients are not faithful people, they are not believers that this is ordeal and test from God… they say that this person did mistakes so he got cancer."

An example of solidarity and support is in what a 46 years old breast cancer patient expressed;

> "Everybody was kind with me, supporting my spirits, was good to me, compassion and cooperative… thanks God."

And what a 70 years old colon cancer patient stated;

> "People… they don't help at all… nothing at all."

Expressed Patients' Needs

Respondents' needs were related to treatment plan, financial support, psychosocial support, and system management. This included good interpersonal, professional, **supportive relationship**; such as telling truth and communicating bad news. A 60 years old male from the south said;

> "They hide the news from me… the doctor had told my children. It was by chance that I heard them speaking, they should told me, because hiding the truth is not good. I hope they told me, that would be much-more nicer and better, but hearing them speaking by chance, that's really bad, it affected me indeed."

Another 34 years old female from the north said;

> "I was calling for somebody to check my I.V canula, I mean, the least thing to ask for, he said: I am busy, call someone else, call the doctor; you see; I feel like I am a bad guest at their home."

It, also, included sharing information, decision making, and health education. A breast cancer patient from Hebron area said;

> "Dealing with the disease is ok for me; I do what doctors are saying, I have no experience in such things. But I like everything to be clear for me; I want to know everything about my case and my disease."

Also, this included availability of medication, diagnostic tests, supplies, and cosmetic prosthetics and materials. One patient said;

> "When the medication is not available, we buy it by cash, and moreover, these tests are very expensive, a thousand and a thousand and eight… it should be available; sometimes we were obliged to do them outside."

Financial support to cover transportation costs, house sanitation, extra expenses associated with disease and treatment such as food and accommodation. A patient from Nablus area who was coming to the south for treatment said;

> "The way from Nablus is very far, I need at least a hundred shekels just for transportation, not counting any food or drink."

Also, this included social and psychological, spiritual and emotional support. One patient said;

> "Every human, especially the patient, needs counseling. But I did not find anybody to cover this need in the hospital."

Moreover, it included **need for support groups**. A cancer patient from Jenin articulated the support of a cancer survival;

> "All cancer patients whom I know had died, but only this woman survived. She had talked to me and helped me, she improved my spirits and morale, she had the disease and she is still alive!"

Also, respondents stressed on **healthcare provision management** related needs such as better waiting time management, referral availability, palliative care availability, enough capacity and facility, and screening and early detection services, workload management and organization of flow of patients especially in the outpatient clinics. A patient who was in several hospitals for treatment for her cancer for the last two years said;

> "It is the order in the outpatient clinics, there is no order; I am usually from 10am till 6pm, also in the other hospital; they thought I am crying because I am angry with my husband or my family… but, I am here since 7am, waiting till 1pm for the result of the blood test… I ask them, but they say: do you think you are the only one at the hospital… indeed, I am the first one here, even before they start their work in the morning… when I do the blood test outside in a lab, it takes five minutes, but they do not accept it."

Other needs related to accessible, well equipped health services. One of the comments was;

> "They took me to Ramallah… they did not have a free bed for me. I wish there is a near treatment center… I wish indeed."

5.4 Summary

The quantitative part main results were the poor GQoL (41.8%), the poor functionality, and the severe symptoms of the Palestinian cancer patients. These included fatigue (66.6%), pain (63%), and insomnia (56.4%), financial difficulties (64.6%). Many socio-demographic and clinical factors found to be statistically significant at ($p<0.05$) in relation to the GQoL, QoL functions, symptoms severity, and financial difficulties. The most common factors were stage, educational level, department of care, region, and monthly income. Other significant relationships were between GQoL with FA, NV, PA, DY, SL, AP, CO, DI, and FI. Moreover, there was a significant relationship between educational level of participants and their cancer stage. Predictors of poor QoL were advanced stage of cancer ($\beta= -0.37$, $p<0.001$), low income ($\beta= 0.19$, $p=0.001$), low educational level ($\beta= 0.12$, $p=0.04$), and long duration of treatment ($\beta= -0.12$, $p=0.04$).

The qualitative part of this study generated eight themes which were affecting respondents' daily life, personal perceptions of cancer, factors affecting coping status with cancer, patients' beliefs regarding treatment, barriers to service delivery, satisfaction of patients, patients' needs, and community perceptions of cancer patients.

The results of this study are supporting the need for palliative care service for those patients to control their pain and symptoms in order to improve their QoL, the need of integrating palliative care within the Palestinian healthcare system and health policies, and provided base line data of the QoL of cancer patients in Palestine.

Chapter Six

Discussion and Conclusion

6.1 Introduction

This study provides basic understanding of factors affecting the Palestinian cancer patients' perception of their QoL and their symptoms management. Also, it assessed the scores of the Quality of life domains of cancer patients in Palestine using a statistically significant and representative sampling size. As well, it included a qualitative part, which provided some vital information that is unique and specific to the Palestinian cancer patients.

Moreover, it identified predictors of poor QoL and functions. This is important because this is how we can prioritize our endeavors toward improving the QoL of cancer patients, particularly under current economical, social, and political conditions.

The following sections discuss the main results of this study; it includes QoL of Palestinian cancer patients and the factors affecting it, the predictors of poor QoL, comparison with other studies in the same field, as well as, some other issue that was highlighted through the study such as significant family role and the desperate need for palliative care integration within the national health care system. Moreover, recommendations for policy makers, healthcare organizations and researchers were highlighted.

6.2 Quality of Life of respondent cancer patients

QoL of the respondents were very poor (41.8%) in comparison with other studies from the region. Also, when using the 33% cut-off point the majority of respondents (79.4%) were below the good functioning point. In a study in Kuwait, the GQoL was 45.3% with poor to average functioning (Alawadi & Ohaeri, 2009). In Turkey, Pinar et al (2003) GQoL was 66.2 out of 100 points. In a study in Iran, QoL was fairly favorable (66%) or favorable (23%) in cancer patients (Dehkordi et al, 2009). This was statistically and clinically significant and reflected on all aspects of patients' life.

Also, there was significant relationship between QoL and educational level, income, department of care, stage of cancer, duration of treatment, and region. As well as, there were significant effects on QoL from FA, NV, PA, DY, SL, AP, CO, DI, and FI. Predictors of QoL were respectively arranged according to degree of effect as the stage of cancer (β= -0.3, $p<0.001$), monthly income (β= 0.19, $p=0.001$), educational level of patient (β= 0.12, $p=0.04$), and duration of treatment (β= -0.12, $p=0.04$). Moreover, QoL was worse than national and international data (Dweib, 2011; Samara & Saca, 2009; Alasadi & Ohaeri, 2009; Pinar et al, 2003; Scott et al, 2007).

In this study, there was no significant relationship between GQoL and place of treatment, house ownership, living condition, and marital status, person taking care of the patient, place of residence, age, and gender. Whereas major associations with HRQoL were found in Kuwait with age, stage of cancer, radiotherapy treatment, and fatigue (Alawadi and Ohaeri, 2009). On the other hand, in Iran, it was found that no correlation present between QoL and age, sex, marital status, duration of disease, economic conditions, educational

level, and occupational function; but, with cycles of chemotherapy (more than 2) (Dehkordi et al, 2009).

In the qualitative part of the study, patients expressed their needs for improved QoL through describing their feelings, satisfaction and needs. This poor QoL results stress the need for intervention to preserve the QoL of cancer patients by better care, early detection, holistic multiple team approach, and better pain and symptoms control. This should be done on all levels including policy maker, health professionals, organizations in the field of cancer care, patient support groups, and patients and their caregivers.

6.2.1. QoL Domains / Functions:

Most of the functions were below the half of the full function. The means were between 46% and 60.5%. Pain and fatigue were found to be significantly and strongly correlated in a negative relationship with all the functions. Also, when using the 33% cut-off point, the majority of cancer patients (especially PF, EF, and SF) were below the good functioning point, which intensifies these results.

General look at the results of this study, in comparison with other studies (table 6.1), presents variations in QoL functions that were lower or within the same level of other studies (Thweib, 2011; Alawadi & Ohaeri, 2009; Samara & Saca, 2009; Scott et al, 2007). This is another indicator for the bad situation for Palestinian cancer patients. This emphasizes the need for in-depth studies to explore in more details all aspects of the cancer patient life and needs.

6.2.2. Symptoms and Difficulties:

The most distressing symptoms and difficulties in this study were fatigue (66.6%), financial difficulties (64.6%), and pain (63%). Also, when using the 33% cut-off point, the majority

of cancer patients experienced very bad symptoms and high financial burden (almost two thirds of the patients were in the high burden area).

Qualitative interviews supported this finding. This was clearly stated by 34 years old cancer patient;

> "I have a lot of fatigue; I feel tired when I take the chemotherapy, sometimes I fall unconscious when I am at the hospital, also, there is pain in my back… I can't take it anymore, all the times I am in the bed"

Other studies presented similar findings. Pain and fatigue were the most prevalent and severe among majority of cancer patients in many studies. Also, these were found associated with QoL and adverse outcomes such as depression, functional decline, and patient misery (Meier and Brawley, 2011; Alawadi & Ohaeri, 2009). On the contrary, Pud et al (2008) found better QoL in patients with less fatigue and pain.

This was indicator of the harsh conditions that the cancer patients live in, especially within the Palestinian context under the known fact of poverty and the Israeli occupation policies, which is affecting access of users to care.

In summary table (6.1) shows that Palestinian patients QoL is the poorest if compared to Kuwait, Turkey, and UK cancer patients.

The poorer QoL of Palestinian cancer patients on comparison might be due to the deteriorating socio-economic and political situation in the country, or lack of professional and specialized care to support cancer patients.

Table (6.1): Comparison of GQoL, QoL functions, most severe symptoms, and financial difficulties of cancer patients in different studies.

	Current study Palestine (Khleif, 2012)	QoL Cancer Palestine (Thweib, 2011)	QoL Breast Cancer Palestine * (Samara & Saca, 2009)	QoL Breast Ca Kuwait (Alawadi & Ohaeri, 2009)	QoL Cancer Turkey (Pinar et al, 2003)	QoL Cancer UK (Scott et al, 2007)
GQoL	41.8%	48%	49% *	45.3%	66.2%	63.8%
PF	48.5%	47.8%	55.4% *	52.6%	---	79.7%
SF	50.0%	49.2%	45.8% *	61.2%	---	72.4%
EF	46.0%	48.4%	44% *	60.3%	---	74.9%
CF	60.5%	57.6%	---	59.9%	---	82.7%
RF	48.8%	47.8%	---	55.1%	---	55.1%
Most severe symptoms	FA (66.6%) PA (63%) SL (56.4%)	SL (59.5%) FA (59.2%) PA (58.5%)	Spirituality	PA, DY, SL, and AP	---	FA, PA
FI	64.6%	52.3%	---	---	---	---

*In this study, results were calculated using linear transformation of the Likert scale.

6.3 Factors associated with poor QoL and worse Symptoms

Many factors identified through this study to be associated with poor QoL and worse symptoms and difficulties. These were grouped into sociodemographic factors and clinical factors as follows.

6.3.1. Associated Sociodemographic Factors:

These included the factors that were mostly discussed in the literature as associated factors with QoL of cancer patients. These were gender, age, marital status, education, income, and region.

Gender

Distribution of females to males in the study sample (58.2% to 41.8%) was similar to that of the cancer patients' distribution in Palestine (54.3% to 45.7%) according to MOH report of 2011. But gender was not statistically significant with any of the QoL domains or symptoms. Also, there was no difference noticed in responses of patients to in-depth-interviews between males and females in expressing their needs or satisfaction. However, Guner et al (2006) found in their study of Turkish cancer patients that women perceive less negative impact of cancer on their lives than men do.

Age

In this study Mean age was 52.7 years (SD=15.2) where younger patients had significant better in their physical and role functions and less fatigue. However, there were no significant relationship between GQoL and age. On the other hand, other studies found that older cancer patients have lower QoL (Guner et al, 2006; Pinar et al, 2003; Koo et al, 2012). On the contrary, Alawadi & Ohaeri (2009) found in their study of Kuwaiti cancer patients that there were more symptom intensity and worse functioning in younger patients.

Qualitative results showed perception of cancer as a fatal disease and representing the end of life, but that was not apparent to be linked to being older. However, Guner et al (2006) stated that older cancer patients believed that cancer is the end of the road and had low expectations of themselves as well as of the society, the thing that negatively affected their QoL.

Also, results of this study showed that older patients had more fatigue and poorer physical and role functions.

Marital status and family support

In this study, there was statistical significance between marital status as being married and poor physical function and more financial difficulties. Guner et al (2006) found that highest QoL was in unmarried as they have less family responsibilities, while worst QoL was in widows as they lack the support of both family and spouse.

On the other hand, in the qualitative part, patients expressed high perception and value of family support, help, and encouragement, especially the supportive role of spouse. Also, having children and family was a factor that helped them overcome the disease and gave them power to fight it. Patients stressed on the psychological and emotional effects of that type of support for overcoming the crises of cancer, especially in the absence of any other specialized or professional support system.

This indicates the important role of family support within the Palestinian context; especially that 90.7% of patients in this study are living with their families and 41% expressed that someone from the family members is taking care of them in their sickness. The Palestinian culture and society highly value the solidarity of the community members as a whole, and specifically the close family members. This is unique in the Palestinian culture; people help and support each other on different aspects either physically, socially, emotionally, or even financially. On the other hand, this is sometimes compensating for the missing professional counseling and support system within the health care system in Palestine, due to lack of resources and low level of awareness of patients to the need for such professional support.

Education

In this study, 57.1% of patients were under secondary education, of which 20.1% were illiterates. This was significantly associated with poor GQoL, low functions (PF, RF, SF, and EF) and high FA, FI, and PA. Similar results found in literature; illiterate patients had the lowest QoL scores (Pinar et al, 2003). Guner et al (2006) concluded that better QoL in educated patients may be due to better coping mechanisms, better access, and /or finding and benefiting from resources.

Knowledge is very important in the fight against cancer. Patients expressed knowledge, besides their faith, as the tool that enables them to cope through the in-depth-interviews.

It is clear that educational level has apparent effect on cancer patients' QoL and symptoms experience, and is a predictor for QoL.

Income

The majority of cases (75.2%) were very poor with an income less than 2000 NIS. This is even below the poverty line (2,293 NIS) in Palestine (PCBS, 2012). Also, higher income was significantly associated with better GQoL and QoL domains, and worse symptoms and financial difficulties.

Similarly, higher income was associated with better QoL as patients have better ability to find resources in less burden and stress (Guner et al, 2006; Alawadi and Ohaeri, 2009). In-depth-interviews showed that financial difficulties and associated costs have high burden on cancer patients.

This was exacerbated by the fact that most cancer patients' lose their jobs after they got the disease, besides the extra expenses associated with treatment. In addition, FI was worse for those living in rented houses, living in the south, less educated, in advanced disease stage, hospitalized, and married with more familial responsibilities.

This indicates the need for social and welfare support system for those patients. The government through its ministries, especially ministry of social affairs, has a major role and

responsibility toward such intervention. It was clear that it is not enough to have cancer treatment free of charge, but also to cover associated expenses and financial burden that is unbearable by those vulnerable cancer patients.

Region

In this study, poorer GQoL, EF, PF, SF, and CF, and more fatigue and financial difficulties were found significant in the southern region of the West Bank in comparison with the middle or the northern regions. Also, 58.2% of the cases were from the south. In addition, this was noticed through patients' perceptions of cancer in the qualitative part. A 60 years old lung cancer patient from Hebron area said;

> "I think it is due to the nuclear radiation from the reactor of Dimona in Israel… there are more cases in the southern areas."

This might be an issue, even though; more attention to conditions of patients and available healthcare services are needed.

6.3.2. Associated Clinical Factors:

These included the most apparent factors associated with the QoL of cancer patients. These were stage of cancer, current treatment, department of care, and duration of disease.

Stage of cancer

In this study, (71.4%) had advanced stage of cancer. This is higher than international figures. For example, advanced cancers recorded 59% in Kuwait (Alawadi and Ohaeri,

2009). Moreover, this study found that the stage was significantly high in affecting all aspects of QoL functions and symptoms. This is congruent with literature. Alawadi and Ohaeri (2009) found those with advanced cancer to have worse functioning.

In addition, significant relationship found between stage and educational level of patients. (88.7% of illiterates had advanced stages of cancer, while 57.5% only of university degree patients).

This is an important indicator of the massive need for intensive awareness campaigns, early detection, and education for the community as a whole, and to patients and their families as specific. Moreover, education and training of health care professionals on better detection and classification of cancer is high priority.

Current treatment

The study revealed that the main type of treatment was the chemotherapy treatment (52.2%). There were no significant association between type of treatment and QoL. Similar results found by Pinar et al (2003) in Turkey. On the contrary, Alawadi & Ohaeri (2009) found significant association of radiotherapy treatment with more fatigue in Kuwait.

Department

In this study, the majority of patients were outpatients (73.7%). However, there was significant association between inpatients and poor QoL (functions and symptoms). Pinar et al (2003) also found that hospitalized patients had lower QoL scores than patients treated on an outpatient-basis.

Usually, patients with severe symptoms and worse conditions are hospitalized; however, more attention to them by healthcare providers and managers is needed.

Duration of treatment

This study revealed that majority of patients (62.4%) had long duration with cancer and this had significant effect on patients' QoL. That was not the same in other studies; Pinar et al (2003) found that duration of the disease and type of cancer had no effect on QoL.

This indicates that the longer period with disease the more suffering the cancer patients in Palestine have. This emphasizes the need for more care and attention to such patients to improve their QoL.

6.4 Determinants of Poor QoL

This study revealed that the poorest QoL among Palestinian cancer patients was related to low education, poor financial condition, hospitalization, advanced stage of disease, longer duration of treatment, and living in the southern region. Table (6.2) shows the predictors for QoL, functions, symptoms, and financial difficulties, in which stage, education, and income were the main predictors for almost all of them.

Table (6.2): Statistically significant determinants for QoL (functions and symptoms).

	Significant Determinants (P<0.05)
GQoL	↓ Education, ↓income, in-patient, advanced stage, >6 months treatment, south W.B.
PF	Old, ↓ education, ↓income, widow/divorced, in-patient, advanced stage, >6 months treatment.
RF	Old, ↓ education, advanced stage.
SF	↓ Education, in-patient, advanced stage.
CF	In-patient, advanced stage.
EF	↓ Education, ↓income, advanced stage.
FA	Old, ↓ education, in-patient, advanced stage, >6 months treatment.
FI	↓ Education, ↓income, live in rented house, in-patient, advanced stage, south W.B.
PA	↓ Education, in-patient, advanced stage.

Alawadi and Ohaeri (2009) found that poorer HRQoL scores were associated with younger patients, financial difficulty, social function, role function, physical function, cognitive function, and emotional function. Other studies found predicting relationship between depression and shortened survival (Meier and Brawley, 2011). Scott et al (2007) found that role and social functions have greater influence in Islamic countries than UK. While, Cheng and Lee (2010) concluded that Chinese cancer patients poorer QoL is associated with a cluster of symptoms including pain and fatigue. Rogers et al (2012) found that UK cancer patients with more financial burden are associated with poorer QoL.

These results are of high value in determining the most vulnerable cancer patients within the general population of cancer patients. This would be of great value for policy makers and health care planners, for health care providers and professionals, and for fund raising and allocation. This would help in determining the priorities, especially under the current scarce resources and weak economy in Palestine.

6.5 Important Themes of the Qualitative Part

This study generated many themes from the in-depth-interviews with cancer patients. The most important were the patients' perceptions of their disease and its treatment, patients' expressed needs for better QoL, barriers to service delivery, patients' satisfaction with service delivery, and community perceptions for cancer and cancer patients. Similar domains were generated by other international studies. Shahidi, Bernier and Cohen (2010) found eight domains upon content analysis of 110 answers of terminally ill cancer patients, which were physical condition and symptoms, psychological status, existential, relationships and support, quality of care, physical environment and living facilities, hobbies and daily activities, and finances.

6.5.1. Patients' Perception of Cancer and Treatment:

This study revealed cancer patients' perceived understanding and beliefs toward their disease and treatment. The main perceptions of patients were classified into self-integration with the disease, shame feeling from being a cancer patient, feeling of guilt from being diseased, incurability of cancer, no necessity for pain management, powerlessness against cancer, and linkage of cancer causes with surrounding environment and past events and sins.

Those perceptions were based sometimes on personal ideation, cultural beliefs and values, religious beliefs and faith, misunderstanding, poor knowledge, low level of awareness, or traditional interpretations.

Some of these were apparent in literature as well. Mazzoti et al (2012) found that 58% of patients perceived their disease as severe, while 44% thinks it is difficult to cure. Dehkordi et al (2009) and Mazzoti et al (2012) found that psychological implications of cancer were anxiety, fear about future, thinking about the disease and its consequences, impatience, and depression.

Patients perception usually stem from their knowledge and information available to them. This; off course, emphasizes the need for extensive programs of rehabilitation and training for healthcare professionals in the field of communicating information and supporting patients. Moreover, raising awareness and health education and workshops for patients are highly needed, especially through better use of media.

6.5.2. Patients' Needs for Improved QoL:

In the study, 35% of patients expressed that they did not use other places or other services outside the hospital. This does not imply that they did not need such services; on the contrary, it is an indicator of lack of these services. That is clear through their expressed needs for many services in both the quantitative and the qualitative parts of this study.

One fifth of patients used private sector for needed services, and 31.3% had diagnostic tests and got medication and treatment for pain and symptoms relief outside the treating hospital of cancer. Also, quarter of patients expressed the need for financial aid.

This is of high importance for healthcare system policy makers, as well as for the healthcare providers and professionals. It is clear that patients have huge economic burden on them. This highlights the need for palliative care (PC) service integration into the health system in the efforts toward quality improvement and as a measure that is economically efficient and cost-effective, not only for the patient, but also for the health care system.

A lot of strategies were identified in the literature including; considering PC as a priority public health problem, integrating it into the national health policies and develop national cancer control policy in the national health plan, education and training, drug availability, providing good quality care including home-based care especially as most patients prefer to die at home and not able sometimes to afford coming to the hospital, promoting quality of care toward whole-person quality care, and family social and institutional support (Sepulveda et al, 2002; and Stjernsward et al, 2007a; Meier and Brawley, 2011; Silbermann, 2012; Alawadi and Ohaeri, 2009).

6.5.3. Barriers to Service Delivery:

In this study, the main barriers faced the informants were the expenses associated with treatment, and access to treatment because of the distance, and political barriers (checkpoints, separation wall, and siege) as result of Israeli occupation. A 34 years old patient from Nablus area explained her struggle with access to care to East Jerusalem hospitals;

> "And on my way to hospital I have many, many difficulties… on the metal rotating barriers and at the checkpoints… I have to change my address to AL-Ram because it is easier for me to do the permit paper there. My brothers are all young, and they were abundant and forbidden from passing the checkpoint. I was in Augusta Victoria and Makassid hospitals… patients have their relatives around them, and I was setting alone in my bed like a monkey… I swear by God, I was feeling strangled. I hoped there is anyone of my brothers there… of any family member… that would be of great help."

This reflects the heavy burden that patients have besides their misery of having cancer. This needs urgent intervention from all; including the Palestinian government, the healthcare system policy makers, the donor countries, and the international aid agencies. That might be through providing near and easy access to care, and making sure all required treatment modalities and diagnostic facilities are available. On top of that is to remove the physical

apartheid wall and checkpoints that are preventing patients and families from access to care.

6.5.4. Patients' Satisfaction with Service Delivery:

The main expressed areas of dissatisfaction were with pain management scheme, boring complicated routine, bureaucratic long process to get the referral, favoritism and nepotism, sometimes unavailability of medication and diagnostic testing, poor symptom management and palliative treatment of associated conditions, inaccuracy or delay in diagnosis or test results, and unhygienic environment due to crowding and uncleanness.

The majority of respondents were dissatisfied with services provided by healthcare professionals such as in: psychosocial support, communication and education behavior and ability, attitude and ethics, honesty in telling truth, and sharing in treatment decision making plan. But an important issue was identified regarding producer induced demand of some services with some patients.

This emphasizes urgent need for the MOH to develop healthcare system policies and practices that ensures all needed resources and implements more monitoring on practice, to ensure the preservation of patients' rights.

6.5.5. Community Perception:

In this study, community perceptions were pity feelings with cancer patients, stigmatization of cancer, perceiving it as a fatal and serious disease, considering it as a punishment from God, and sometimes solidarity and willingness to help. In general patients were unhappy with the negative views of the community.

These findings shed light on the importance of community, as well as, the need for awareness campaigns toward better understanding and support for cancer patients in their fight against cancer.

6.6 Conclusions and Implications

These results suggest the need for early detection and awareness among cancer patients and their families, as well as awareness and education of health care providers for better care and symptoms management to achieve better QoL for patients. More important is the desperate need for integrating palliative care into the health care system in Palestine as an economically efficient, cost-effective and quality improvement measure.

This study revealed that the main problem lies within two main streams; the socio-economic factors of the patient, and the ability of the health care system to early detect, diagnose, treat, and provide professional support for cancer patients, such as qualified and trained healthcare providers in palliative care and symptom management. Stjernsward et al (2007a) found that 35 million people around the world are in need and can benefit from PC service.

The integrating of cost-effective palliative care services is seen as solution to the burden on the healthcare system and patients. This can be done through education, training, and awareness to both professionals and patients.

The results of this research are of high importance for healthcare system policy makers and professionals. The results exposed the extremely poor QoL of the cancer patients in Palestine, severe symptoms, and extra financial burden. As well, the study suggested the need for palliative care (PC) service integration into the health system to improve quality of care and as an economically efficient and cost-effective measure.

Uzun et al (2004) suggested incorporating PC and pain management in service delivery for improving QoL of cancer patients. Also, Sepulveda et al (2002) suggested that it is a public health issue to deal with people with cancer in the proper way. Moreover, cancer is the second leading cause of death in Palestine (MOH, 2012), and palliative care and pain

control is a human right (Breitbart, 2011). This emphasizes the importance of such public health need.

Within these endeavors, many gaps defined internationally to bridge in the way to implement PC programs. Of these; are considering PC as a priority public health problem, integrating it into the national health plans and develop national cancer control policy, effective cancer registry, education and training, drug availability, providing good quality care including home-based care especially as most patients prefer to die at home and not able sometimes to afford coming to the hospital, valuing competent palliative medicine, including PC requirements in the training programs of professionals, promoting whole-person quality care, and family social and institutional support (Sepulveda et al, 2002; and Stjernsward et al, 2007a; Meier and Brawley, 2011; Silbermann, 2012; Alawadi and Ohaeri, 2009).

6.7 Recommendations

The results of this research are of high importance for healthcare system policy and professionals. This research is recommending the following notes;

For the policy makers:

1. Considering palliative care (PC) as a priority public health problem, integrating it into the national strategy for cancer.
2. Integrating palliative care service into the health care system within the efforts toward quality improvement, and as a quality measure that is economically efficient and cost-effective.
3. Providing good quality care including home-based care, especially as most patients prefer to die at home.

4. Valuing competent palliative medicine through education and training, and including PC requirements in the training programs of health care professionals.
5. Promoting quality of care toward whole-person quality care; through system redesign and family social and institutional support.
6. Having effective comprehensive prevention programs for cancer, to be implemented through health care system redesign.
7. Improving quality health information systems, especially the cancer registry program, in order to improve data availability and consistency and accuracy. This will facilitate further researches and will provide better quality data for decision makers and stakeholders.
8. Financial support for cancer patients, through effective role of the government ministries, especially the Ministry of Social Affairs.
9. Having PC and symptoms management facilities in all areas around country, especially in the case of cancer patients as they are the most vulnerable population among all patients.
10. Ensuring drug availability, especially those for control and management of cancer symptoms, and adopting essential drug list based on the international essential drug list for palliative care.
11. Promoting health policies toward better advocacy and increasing awareness about cancer, screening, and early detection and treatment. And also address stigmatization of patients.
12. Monitoring system for proper practice and provision of oncology health services.

For the healthcare organizations that provide care for cancer patients:

1. Promoting education on pain management and ensure correcting of wrong beliefs and myths, such as those related to pain management and addiction.
2. Education and training of staff on issues related to PC, pain and symptom management, and communication skills.

3. Ensuring better management of time, especially the waiting at the outpatient departments.
4. Working on formation of multidisciplinary teams, and integrating them in the care of cancer patients.
5. Providing education and training for patients and their families regarding symptoms control and self care, especially at homes.
6. Providing psychological support and education on issues related to disease, treatment, and coping mechanisms with cancer for the patients and their families.
7. Planning health services to consider the entire life perspectives of the patient and not only focusing on the disease itself.
8. Involve patients in the treatment decision making plan.

Further research

1. Prospective longitudinal cohort studies in the field of QoL of cancer patients.
2. Disease specific research studies for different types of cancer; especially for breast and colon cancers as they are the most dominant in Palestine.
3. Further studies in specific fields such as symptom control and pain management availability and skills,
4. Further studies for cancer patients' satisfaction with the provided health services.
5. Assessment of quality of health services provision for cancer patients.
6. More concentration on the cognitive part of the assessment tool, which showed low reliability in this study, as well as other regional studies.

6.8 Summary

The results of this study about quality of life of cancer patients were of high value and importance to the health policy makers and health care professionals in Palestine. Even though these results emphasized the international fact that the QoL of cancer patients is

usually poor and in need for many interventions, this study articulated the problem specifically in Palestinian cancer patients. This study clearly indentified the acute need for development of policy and clinical intervention, especially within the unique Palestinian context under the Israeli occupation restrictions and rules.

Moreover, the results of this study are supporting the need for palliative care service for those patients to control their pain and symptoms in order to improve their QoL, and the need for integrating palliative care within the Palestinian health care system and policy as an efficient tool for reform.

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Meetings and Personal contacts:

- Head of oncology department at Beit Jala Hospital (May 2012): number of cancer cases at the hospital and hospital share of all cancer patients in West Bank of Palestine, Personal contact.

- Oncologist at Beit Jala Hospital (May 2012): number of cancer cases at the hospital and hospital share of all cancer patients in West Bank of Palestine, Personal contact.

- Quality manager at Beit Jala Hospital (May 2012): number of cancer cases at the hospital and hospital share of all cancer patients in West Bank of Palestine, Personal contact.

- In-charge nurse of the chemotherapy unit at Beit Jala Hospital (May 2012): number of cancer cases at the hospital and hospital share of all cancer patients in West Bank of Palestine, Personal contact.

- Head of oncology department at Agusta Victoria Hospital (May 2012): number of cancer cases at the hospital and hospital share of all cancer patients in West Bank of Palestine, Personal contact.

- In-charge nurse of the chemotherapy unit at Augusta Victoria Hospital (May 2012): number of cancer cases at the hospital and hospital share of all cancer patients in West Bank of Palestine, Personal contact.

- Patients' services manager at Augusta Victoria Hospital (May 2012): number of cancer cases at the hospital and hospital share of all cancer patients in West Bank of Palestine, Personal contact.

- In-charge of Medical records at Augusta Victoria Hospital (May 2012): number of cancer cases at the hospital and hospital share of all cancer patients in West Bank of Palestine, Personal contact.

- In-charge nurse of the chemotherapy unit at Watani Hospital (June 2012): number of cancer cases at the hospital and hospital share of all cancer patients in West Bank of Palestine, Personal contact.

- In-charge of the records office at AL-Watani Hospital (June 2012): number of cancer cases at the hospital and hospital share of all cancer patients in West Bank of Palestine, Personal contact.

- Cancer registry respondent person at Ministry of Health (May 2012): number of cancer patients in West Bank of Palestine, Phone call.

Annex (1): Pearson's correlation: The relationship between GQoL and symptoms associated with cancer.

		Fatigue	N&V	Pain	Dyspnea	Insomnia	AP	Constipation	Diarrhea	FI
Global health status/ QoL	R	-0.620	-0.391	-0.622	-0.423	-0.447	-0.387	-0.332	-0.224	-0.393
	Sig. (2-tailed)	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001
	N	308	305	308	311	311	311	313	314	314
Fatigue	R		0.427	0.775	0.467	0.500	0.515	0.415	0.204	0.376
	Sig. (2-tailed)		< 0.001	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001
	N		302	304	308	308	308	310	310	311
Nausea & vomiting	R			0.382	0.340	0.279	0.554	0.327	0.251	0.196
	Sig. (2-tailed)			< 0.001	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001	0.001
	N			305	310	309	309	310	308	308
Pain	R				0.429	0.502	0.445	0.382	0.205	0.425
	Sig. (2-tailed)				< 0.001	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001
	N				309	308	308	310	310	310
Dyspnea	R					0.335	0.352	0.246	0.167	0.331
	Sig. (2-tailed)					< 0.001	< 0.001	< 0.001	0.003	< 0.001
	N					314	314	316	314	314
Insomnia	R						0.417	0.239	0.187	0.230
	Sig. (2-tailed)						< 0.001	< 0.001	0.001	< 0.001
	N						315	316	314	314
Appetite loss	R							0.355	0.263	0.239
	Sig. (2-tailed)							< 0.001	< 0.001	< 0.001
	N							316	314	314
Constipation	R								0.107	0.242
	Sig. (2-tailed)								0.058	< 0.001
	N								316	316
Diarrhea	R									0.140
	Sig. (2-tailed)									0.013
	N									317

Annex (2): Thematic Analysis table of the In-Depth-Interviews.

#	Categories	Themes	Subthemes	Quotations	Original Arabic statement
1	**Effects of disease on daily life**	Physical effects	Helplessness Pain Helplessness Helplessness Role confusion	C1: all my strength collapses; I didn't have the power to stand to drink water. The pain is the worst; even it is worse than cancer itself. C8: I have a lot of fatigue; I feel tired when I take the chemotherapy, sometimes I fall unconscious when I am at the hospital, also, there is pain in my back… I can't any more, all the times I am in the bed.	ح1: بتنهار قوتي كلها، ما كان عندي قدرة اقوم اشرب.. الالم اشد شيء، حتى هو اشد من المرض نفسه. ح4: والله في وجع.. الوجع موجود. ح6: اثر المرض.. اخر ما كان بطلت اقدر له.. انا اللّي ذابحني النزيف بس.. الم كثير. ح8: بتعب كثير.. لمّا باخذ الكيماوي بتعب.. احيانا يغمى عليّ وانا في المستشفى.. و بصير ألم في ظهري.. بطلت اقدر.. بظل قاعد على التخت. ح9: أرهاق.. بتعب.. ايدي بتورم.
		Social effects	Role confusion Role performance Projection	C1: the most important thing to me is to be with my kids; their feelings were abnormal, I was away outside home, I was taking hypnotic and sleep for hours, they were lost in that era.	ح1: اهم شيء عندي اكون موجودة مع ولادي.. شعور اولادي كان غير طبيعي.. كنت اغيب برة البيت.. اخذ منوم و انام ساعات.. في فترة ضاعوا. ح2: بناتي لساتهم صغار.. بدورن علي كثير.. بقدرش اقوم فيهن. ح5: الاولاد بخافوا.. العيلة بخافوا. ح7: الّي عندو مريض كل العيلة بتتأثر. ح8: الكل مشغول فيّا.. أهلي عدموا حالهم عليّ.
		Financial effects	Role performance		ح4: اثر المرض.. طلب الدار.. انت مش غشيم.. الظروف صعبة.

		Sexual life effects	Hopelessness Role performance	C1: I have no desire, I don't think about it, actually nothing is between us now. Actually I asked for divorce before I had my surgery. C7: After chemotherapy, I feel tired when I am back at home. Off course, this cause indolence and frigidity at home… whatever, it has an effect.	ح1: بطل عندي رغبة.. ما في اشي بيننا.. مش في بالي افكر في هالشيء.. انا طلبت الطلاق قبل العملية. ح4: المرض اثر كثير عليّ و على عيلتي.. يعني طبعا أثر. ح7: هادي العلاج الكيماوي.. برجع الواحد تعبان على البيت.. الّا يعمل جو خمول في البيت.. الّا يأثر مهما يكون الواحد.
		Psychological effects	Helplessness Death anxiety Adaptation	C6: They told me you are in need for urgent surgery; I was terrified… how they are going to open my abdomen!? So, I ran away for six months, then I was deep down tired, so, I said do it and open my abdomen… if I'll die, let me die.	ح6: قالوا بدك تسوي عملية عاجلة.. انا خفت.. قلت كيف بدهم يسطحوني.. شردت ست تشهر.. بعدين برخت.. قلت خلص اصطحوني.. بدي اموت.. اموت. ح8: أوّلها عدمت حالي.. و هالحين حياتي موقفة بس في المستشفى. ح10: المرض اثر كثير.. رجعنا لورا.. لمّا اجاني المرض سوّالي كل المشاكل.
2	**Personal perceptions of the disease**	Self integrations	Empowerment		ح1: بعد المرض صار عندي عزيمة جديدة.. و شخصية جديدة.. كنت اساعد الناس و المرضى.
		Shame			ح1: بتظللها نقطة حساسة، يعني الوحدة بدها تروح تطلب؟. .انا ما بحب حدا يعطف علي ابداً.
		Guilt	Loneliness	C2: Indeed, I am the only one with cancer in all my area of living.	ح1: انا بزعل على نفسي بالنسبة لجوزي. ح2: يعني في المنطقة اللي انا فيها انا الوحيدة اللي فيها هذا المرض.

		Belief / understanding	Death anxiety Fear of unknown Uncertainty Helplessness Death anxiety Uncertainty Spirituality	C1: I don't think there is complete cure for cancer… I think my disease was caused by hormonal therapy for infertility, or some people are saying it is the nuclear weapon of Israel and its factories in Dimona. C3: I think I am going to die and that's it, this disease means death and I am already going to die… actually, all those with this disease are died. C4: The disease cause is from God, it is not shame or demerit, it is mercy; our God is testing us by the disease, it is mercy and expiation of sins.	ح1: كنت بفكر انه نهايتي حتمية.. الالم ما في دواء يقدر له.. الواحد بصير عندو ادمان عليه (المورفين).. خايفة (افحص) لانه في العائلة هذا المرض موجود. ح1: شفاء بالكامل (للسرطان) لأ، لا اعتقد.. سبب مرضي هرمونات علاج العقم.. كمان بقولوا النووي في أسرائيل، و من المصانع.. من ديمونا. ح2: دايما في البداية بستصعب الواحد .. بس مع المدة لازم يتقبل المرض.. بجوز لاني مش فاهمته كثير بفكرش فيه.. لازم الواحد يرضى بقضائه.. رظيت ولا ما ارظيت.. لازم يصير. ح2: الشفاء من المرض حسب معنويات الانسان.. سبب المرض بجوز ابتلاء.. بجوز ذنوب. ح3: بفكر اني بدي اموت و خلص.. هذا المرض يعني موت.. وانا خلص بدي اموت.. يعني كل اللي صابهم هذا المرض توفّوا. ح3: بعرفش منين بيجي.. بيقولوا من الأكل و من الادوية اللي برشوا فيها. ح4: سبب المرض.. والله هذا من الله.. فش فيه عيب.. هذا رحمة.. ربنا بمتحنّا بالمرض.. رحمة و تكفير ذنوب. ح5: كلها شغلات من رب العالمين.. بخاف شويّ.. المرض هاظ بخوف.. هذا أمر ربنا.. بده الواحد يتقبل الموضوع و يسلم أمره لربنا.. اعقل و توكل.

			Uncertainty Spirituality Uncertainty Uncertainty Helplessness	C8: I am feeling that I'll be taking treatment for all my life; indeed I am not aware of the cause of this disease. C10: I think it is due to the nuclear rays from the reactor of Dimona in Israel… there are more cases in the south.	ح5: هذا المرض نهايته معروفة طبعا.. الحمد لله.. انا متقبل.. بعدين الاعمار بيد الله. ح5: ما بعرف سبب المرض.. في ناس بقولو التدخين.. وفي ناس بقولو القهوة.. يعني في شغلات كثيرة. ح6: السرطان هذا انا عارف.. هي عدوية.. ابصر من وين اجت.. و بقولوا هذا شو اسمو النووي قريب منّا.. انا داري.. هذا المرض لمّا يصيب خلص.. ما الك الّا الله. ح7: سبب المرض انا بقول من الأكل اللّي الواحد بياكله.. الظروف البيئية المحيطة فيه.. او اليهود الهم أثر.. بزرعوا الخضرة كلها مواد كيماوية.. بعدين المعلبات و المكبات الكيماوية كمان. ح8: حاسّة انّي رايحة أظلني طول حياتي وانا أتعالج.. والله ما بعرف شو سبب هالمرض. ح9: سبب المرض بحكو انه بعد فترة من حبوب منع الحمل.. ممكن بس مش اكيد. ح10: أنا بتوقع انه هاد من شعاع النووي تاع ديمونة أسرائيل.. كل ما تروح للجنوب في منه زيادة عن اللزوم.
3	**Factors affecting adaptation with disease**	Commitment/ goal in life	Role strain Emotional	C2: The person lives in this life mostly for her kids; especially that they are girls.	ح2: الواحد اكثر اشي بعيش عشان اولاده.. بالاخص انهن بنات. ح3: كنت بس بفكر في اولادي.

		Personal factors	Empowerment Helplessness Acceptance	C9: What helped me was that I know what my disease is, and I believe it is easier than other types… thank God, I am patient and acceptant… may God cure us by Doaa (supplication).	ح1: صار عندي القدرة اقاوم اي صدمة لقدام. ح2: وجود بيت لحالي منيح ... كنت قبل اخد الدوا اكون مجهزة كل اشي في البيت. ح3: وجود الخصوصية و البيت الخاص كان منيح. ح6: بصبر.. شو بدي اعمل.. بصبر.. حكمة ربنا. ح7: بس الواحد يحاول يبتعد عن كل اشي بضر.. بعدين الزعل و المعنويات العالية.. هاد بأثر سلبي او ايجابي في تقبل المرض. ح9: ساعدني اني عارف شو هو مرضي.. وبقول هذا المرض اسهل من اشي تاني.. الحمد لله.. أنا صبورة و متقبل.. وربنا يشفينا بالدعاء.
		Religious belief / faith	Spirituality Faith Helplessness Helplessness		ح2: بس الشفا من ربنا.. ايماني بربنا قوي. ح3: كنت اصلّي.. بقرأ قران.. بساعد. ح4: اللّي من الله منيح.. الحمد لله.. الأيمان اللّي ساعدني. ح5: الحمد لله.. نفسيتي مرتاحة جدا.. و مسلم أمري لرب العالمين.. بعدين الأعمار بيد الله اول اشي.. بعدين مفش مفر.. الأجل مخطوط سواء بالمرض او بغيره. ح5: امشي بالعلاج و ربنا هو الشافي. ح6: والله يوم الله بلطف بلطف.. كل شي عند الله.. والله ربنا حكيم.

			Faith Faith Helplessness Helplessness	C10: Faith in Allah (God) helped me through; he is the cause and the cure of the disease… firstly, we are in the hands of God; he is "AL-Shafi" the healer… and the person needs to accept it, needs to be faithful in God… for me, this is before everything, even before treatment.	ح7: عمر المرض ما بموت صاحبه.. الّا انتهاء الأجل.. يعني الواحد يخلّي ايمانه بالله كبير.. القران الكريم احسن علاج. ح8: المرض مش عقاب.. لأ.. رحمة.. لدرجة انّي سألت الشيخ.. حكالي من فقد أحدى حبيبتيه في الدنيا عوّضه الله بهما في الجنّة.. انشاء الله. ح9: يعني بتحمّل.. موكلة امري لله.. ومعنوياتي كاملة.. الحمد لله.. انا زي ما تقول انسانة مؤمنة.. يعني هيك من كثر الدعاء ربنا يصبّرني. ح10: ساعدني الأيمان بالله.. اللّي حطّو بشيله.. مسلّمين أمرنا لرب العالمين درجة أولى.. الشّافي هو الله.. بدّو الواحد يتقبّل.. بدّه يكون مؤمن بالله.. عندي اياها قبل كل شي.. قبل العلاج.
		Support system	Social and familial support Support system	C3: All of them helped me… my husband, my relatives, and the neighbors... thank God, but the help of my husband was the most. They were all with me on the day of my surgery, which really made me relaxed; I went into the surgery calm and reassured as	ح1: اخي هدفه انه تظل عزيمتي قوية و حياتي طبيعية.. والدتي كانت تيجي معي (مرافق).. بنت خالتي (ناجية سرطان) اتصلت عليّ قبل الكيماوي و قالت ما تخافي.. هذا ساعدني.. بساعد (المجتمع) مرات، خصوصاً الأهل و القرايب. ح2: خواتي بساعدوني.. لما الواحد الناس بهتمو فيه بحس معنوياته احسن. ح3: كلهم ساعدوني.. جوزي و قرايبي و الجيران.. الحمد لله.. بس جوزي اكثر اشي.. يوم العملية كانو كلهم معي.. ارتحت كثير.. دخلت على العملية و انا

				they were around me… off course; the family provides help, thanks God. C6: I swear by God that nothing helped me at all, no body except of my children who helped.	ح5: العيلة والقرايب و الاصحاب ساعدوني.. كانو يشجعوني.. ما احتجت حدا مختص.. الكل شجعني ما تخافش. ح6: والله ما اشي ساعدني من مرّة.. ولا حدا ما عدا هالاولاد ساعدوني. ح7: جوزي من النوعية اللّي بساعد.. يعني هو اكبر افادة في حياتي.. والكل وقف معي.. الحالة النفسية اهم شي.. كلهم شجعوني.. برفع معنويات الواحد. ح7: برفع المعنويات اللّي حواليك.. العيلة و الزوج و الأهل. ح8: لوما جوزي صابر عليّ و متحملني.. وألا كان ما تحمّلت حالي.. كان زمان موتت حالي. ح9: كانوا ينصحوني.. يعني يرفعوا من معنوياتي.
			Professional support	C1: The nurse is the one who was helping us, he is the one who is giving us the treatment and he is the one who is providing advices and education.	ح1: الممرض هو اللّي كان يساعدني.. هو اللّي بعطينا العلاج و هو اللّي بعطينا النصائح. ح9: كان يقول النا الكل بوخذ.. والكل هيك.. يعني يخلّي الأطمئنان على قلوبنا.
4	**Patient's believes regarding treatment**	Toward Curative medicine	Pain feeling	C7: last thing, I had severe pain in my abdomen and in my back, maybe due to the large amount of medication which I am taking; as any medication affects the liver, and I am trying to avoid such thing and take care… maybe I should bear the pain better that bearing the medication.	ح4: اعقل و توكل. ح7: اخر شي صابني وجع بطن و ظهر كثير.. احتمال من كثر الأدوية.. مهو كل علاج بأثر على الكبد.. والواحد بحاول يتواقى ويدير باله.. يعني الواحد يمكن يتحمل الوجع اكثر ما يتحمل الأدوية.

		Toward Integrative/ alternative medicine	Hopelessness	C3: They told me take Anise, Chamomile, and other herbs… with no benefit, no benefit at all.	ح1: كانو يقرأولي على مياه و اشرب منها.. و شربت حليب الناقة. ح2: شربت حليب نياق.. بحكو منيح. ح3: كانو يحكو خذي يانسون.. بابونج.. اعشاب.. ما فاد.. عالفاضي. ح5: انا بامنش في هاي الروحانيات تبع الشيوخ.
5	**Barriers to service delivery**	Economical barriers		C1: The transportations are not covered by the insurance, as well as accommodation and food.	ح1: المواصلات ما بغطيها التأمين أو النوم و المصاريف.
		Political barriers		C8: And the way to hospital has many, many difficulties… on the metal rotating barriers and at the checkpoints… too much. I have to change my address to AL-Ram because it is easier for me to do the permit paper there. My brothers are all young men, and they were abundant and forbidden from passing the wall checkpoint. I was in Augusta Victoria and Makkasid hospitals… everybody has his relatives around him, and I was setting alone in my bed like a monkey… I swear by God, I was feeling strangled, I hoped there is anyone of my brothers there… of my family… that would be of great help.	ح1: تغلبت لما كنت اروح على القدس. ح2: لازم اعمل بت سكان في اسرائيل.. و جوزي تغلب في التحويلة.. و ما بعرف اذا في لسة منع امني. ح8: و الطريق فيها غلبة كثير كثير.. على المعّاطات و على المعبر.. يعني كثير.. غيّرت عنواني للرام عشان اعمل التصريح هناك اسهل.. اخواني كلهم شباب.. كانوا يمنعوهم يمرّوا على المعبر.. كان في مستشفى المطلع و المقاصد.. كل الناس حواليهم اهلهم.. وانا زي القردة قاعدة لحالي.. والله العظيم.. احس اني مخنوقة.. لو في حدا من اخواني.. من أهلي.. بساعد كثير. ح9: أاه.. في غلبة.. من المحاسيم.. أطلع من بيتي الساعة ثمانية والله.. مرات يأذّن العشاء وان في الطريق.. بس شو بدنا نسوي.

					ح10: التصاريح.. اااه.. غلّبونا.. أول شي اجاني مرفوض أمني.. رفضوني أنا.. بعديها أجا تصريح يوم واحد.. غلّبونا والله.. غلبة تتدخل القدس.
		Distance barriers		C1: I hope if they can provide bus to take us to hospital, I am not satisfied with the distance I travel, it is hard for me.	ح1: لو انه يوفروا باص (للوصول لمركز العلاج).. مش مرتاحة مع المسافة.. صعبة علينا. ح5: يعني مشوار الطريق بغلب شويّ.. اليوم كانت رايقة فش محاسيم.
		Policy & regulation		C1: I hope there is nearer chemotherapy treatment for us in Hebron.	ح1: ياريت يكون علاج كيماوي قريب في الخليل.
6	**Satisfaction with service delivery**	Satisfaction with personnel	Medical treatment plan and pain management	C2: The doctor had said to me not to take medication for the chemotherapy treatment, but only Paracetamol, they told me to take that for pain, indeed, it did not work it out, it was good in decreasing headache… I was immobile and struggling with pain for days. C4: I have good trust in the team, they are good… excellent, the nurse here is extra excellent.	ح1: بطلب منه دواء للعظم ما بعطيني الا مسكنات تروفين او اكامول.. ما كان يفحصني (طبيب العيادة) كان يكتب الروتين و بس.. و لازم اطلب انا الدواء و الفحوصات، و اذا ما بطلب ما بعطوني شيء. ح2: كان الدكتور يقلي ما توخذيش علاج للكيماوي.. بس اكمول.. قالولي خذي اكامول للوجع.. ما كان يخفف.. كان يخفف من الصداع.. كنت اقعد ايام موجوعة و مش قادر اتحرك. ح3: اعطاني الدكتور حبوب.. ما زبطش.. ارجعت عنده قلّي فش غير هاذا الدوا.. قلّي بدك دوا للمعدة.. امشي اتحركي.. خذي سوائل.. فواكه خضار. ح4: ثقتي كويسة فيهم.. كوسيين.. ممتازين.. الممرض ممتاز جدا.

				C8: There is medication for pain… or maybe there is not… I don't know. When I have pain, they told me you will get used to it with time and the pain will fade… just like that, as they were postponing my patience.	ح5: الطاقم الصحي كان اله دور.. شي طبيعي.. نصحوني. ح6: باجي و بروح والله ما نافعني حاجة.. والله ما نفعوني من مرّة.. لا دكاترة ولا غيرة.. اي الدكتور عمره ما كشف عليّ.. عمره ما صابني.. بس بقول بدك هيك و بدك هيك.. اي هو الدكتور ما بكشف؟ ح6: للوجع.. لا.. بقولك بعطونيش ولا اشي.. الحمد لله. ح7: اعطوني مسكنات للألم.. بس مش اكثر.. بس ما كانت تكفّي.. بعدين هدول بعملوا تجارب.. وقّف كل الدوا و حط دوا جديد. ح8: دواء للألم.. في.. ولّا مافشّي.. ما بعرف.. انا لمّا بتألّم بحكولي مع الوقت بتتعوّدي عليه و بروح الألم.. هيك يعني.. كأنّه تصبير. ح9: المسكنات كانت تكفّي.. بعد الكيماوي يعطيني ادوية و أطيب.. الحمد لله الخدماتةالصحية كانت ممتازة.
			Producer induced demand	C7: We have insurance, but firstly we had gone to a private doctor who transferred us to a private hospital. This is not good point from the doctor… he knew that we got insurance, and we are poor, and the surgery costs a lot. He was supposed to refer us to the governmental hospital, they can do the surgery not less	ح4: بتعب من العلاج بعض مرات.. الدكتور قلّي هذا اشي طبيعي.. اذا بصير عندك اشي على طول بتحكي معي و بتيجيني على العيادة. ح7: احنا معنا تامين.. رحنا اول شي على دكتور خاص و حولنا على مستشفى خاص.. يعني هاي نقطة غلط من الدكتور نفسه.. عرف انه معنا تأمين و حالتنا على الله.. والعملية مكلفة.. كان

				competently, they should refer us… but they didn't. They let us stay at the private hospital and we did pay a lot of money	
			Psychosocial support and supportive communication Seeking help	C1: The doctor informed me that it is a small lump, and you have to decide with your family… imagine, I was born again, I took my decision. This is a human being, speaks out principles of human feelings… indeed, I am no-more sick after that.	ح1: الدكتور حكالي انه عندك سرطان بدون مقدمات، و انه بدو استئصال، امي غميت و انا غميت.. انهرت.. ليش حكالنا هيك الدكتور، سببلي هزة ارضية. قال لي (طبيب اخر) كتلة صغيرة.. و انتي و اهلك بتاخذو القرار.. اتخيلي انا ارجعت مولودة من جديد.. اخذت قراري.. هذا انسان بحكي بمبادئ بتخص احاسيس البشر.. يعني لو انا مريضة ببطل مريضة. الممرض هو اللّي كان يساعدني.. هو اللّي بعطينا العلاج و هو اللّي بعطينا النصائح.. ما في عندنا (اخصائي نفسي او اجتماعي). ح2: يعني في ناس محترمين و في ناس بتنفتروا في الواحد. ح3: ما حدا ساعدني. ح4: فش حدا ساعدني.. ساعدت نفسي بنفسي. ح5: عرفت كل اشي.. ما حدا خبّا عني اشي.. الشباب اللّي بشتغلو محترمين.. يعني بتلاقي في ناس جلفة شوي.. بشكل عام جيدين.. انا ارتحت في التعامل معهم جدا جدا.

				C8: As he was telling me you have flu… just like that… in coldly lethal nerves, he was telling me: you have a malignant cancer in your brain… on the spot, I was on the ground unconscious. When I was awake again, my brother carried me out to the car, and said: don't listen to him, there is nothing. Then, when they informed me it is for surgical resection, it was again as the first time to tell me that I have cancer… it was like madness, two times, I was informed the same way, as nothing serious.	ح6: المنيحين ماشيين بقلب و رب.. بديرو بالهم على العيّان.. واللّي مش منيحين.. بطنّشوا.. في واحد هاظ الممرض ذهب.. صاحبي تمام. ح7: يعني في دكاترة.. تلفون ازا الواحد اعتاز ما بعطوه. ح8: بسأل الدكتور على التلفون بحكيلي.. يعني بفيدني. ح8: كل ما اجي بقولولي الفين دينار دواكي.. يعني زي تحميل جميلة.. طب انت دافع من جيبتك.. يعني هذا بغص على قلبي.. كل ما اجي بحكيلي نفس الاشي.. اتحمّلي انت مش دافعة.. كلّه على التأمين. ح8: يشرحولي.. بس انو يفهموني مية بالمية لأ.. أحس انو في اشي.. بس هم ما يحكولي.. كانوا يحكوا لجوزي.. يوخذوه لبرّة و يقولوله اذا عاشت بعد ساعتين أحمد ربّك.. و هي الي سنتين. ح8: كأنّه بحكيلي عندك رشح.. هيك.. ببرودة أعصاب قاتلة.. بحكيلي عندك مرض خبيث في الدماغ.. فأنا طب.. غميت.. تا صحيت على حالي.. أخوي حملني و وداني على السيارة.. قلّي تردّيش عليه.. فش اشي.. بعدين لمّا حكولي استئصال.. كانه هسّة حكالي مرضتي من جديد.. زي الجنون.. مرتين.. ولا اشي.. هيك عادي عادي.. حكولي. ح9: أتصل في الدكتور أساله يجاوب.. أطمئن.

			Health education & awareness	C7: Indeed, the nurse had all the praise, even more than the doctors themselves. Because the doctors write the treatment and they go, while he gives us the advices, for all patients, not merely me, but for all … may God reward him all the best for us.	ح1: لكن الأطباء ما كانو يقولو الي (عن المرض).. الممرض كان يعطينا الارشادات الطبية. ح2: بس بدون اسئلة ما كان حدا يحكيلي اشي.. بس اذا بسال. ح3: ما كان في شرح ولا كتيبات. ح4: ما كانو يعطوني ارشادات. ح5: شرحولنا كل اشي. ح7: والله الممرض كان اله كل الفضل.. اكثر من الدكاترة نفسهم.. لأن الدكاترة بكتبوا العلاج و بعدوا.. اما ابو محمد بعطينا النصائح.. لكل المرضى.. الله يجازيه كل الخير عنّا.. مش بس الي.. للجميع.
		Satisfaction with medical equipments & supplies & service	Diagnostic tests	C5: There are some tests available in the government, but others are available outside, not all tests are available.	ح1: اخوي بدو يهدم المستشفى لانهم ما شخصوني بدري. ح5: في فحوصات في الحكومة و في خارجية.. مش كلها متوفرة.
			Medication	C4: The essential medication is available here, but the other medication; we need to buy it sometimes from outside pharmacies. The treatment is OK; sometimes there are some shortages, but not all the times.	ح1: الدواء متوفر.. بس مش دايماً..بقول الك اطلع اشتريه من برّة. ح2: دايما فش العلاج المناسب.. بس مرات بكون موجود. ح4: الدوا الاساسي موجود هان.. بس الدوا الثاني منشتريه مرات من الصيدليات من برّة.. العلاج كويس.. بعض مرات بكون في اشي ناقص.. بس مش دايما.

					ح5: العلاج متوفر.. ما كان عندي مشكلة. ح6: مهو بقى فش علاج.. مش كلها موجودة. ح7: الدواء.. مش دايما.. في فترات ما بكون موجود. ح8: احيانا الدوا يكون مش موجود.. اموت تأصل المستشفى و أرجع.. كثير بعطوني الروشيتة و مش موجودة.. فبشتريها من برّة.. كثير كثير.
			Environment	C2: The patients are crowded over each others, there is no privacy. The government and the hospital need to enlarge the patient care areas, so to comfort the patient, it is better for his self-esteem and psychology… indeed, when I came to the hospital I get sick.	ح1: النظافة تعيسة. ح2: المرضى فوق بعض.. ما في خصوصية.. لازم الحكومة و المستشفى يوسعه اكثر عشان المريض يوخذ راحته.. احسن لنفسيته.. يعني لما باجي عالمستشفى بامرض انا. ح3: الخدمات الصحية منيحة.. الحمد لله.. متوفرة و نظيفة. ح8: الحمّامات ثلاث ايام زي ماهي.. نظافة فش من مرّة.. عدم.. انام على السرير.. تكون البسّة نايمة تحت السرير.
		Satisfaction with Referrals system		C2: We did the surgery in private and paid for it, because it was not available here in the governmental hospital. We have insurance, but they kept delaying us… and the doctor advised me not to delay my surgery more, he said: it is not good for you. So, we did it outside.	ح1: مادياً التأمين بغطي (كلفة العلاج). ح2: عملنا العملية على حسابنا لانو ما توفر النا عملية هان (في المستشفى).. معنا تامين .. بس ظلوا ياجلوا فينا.. و الدكتور قلي ما تاخري حالكي.. مش من صالحكي.. فعملناها برّة. ح3: اعطونا تحويلة.. لقبل العملية بيوم.

					ح4: ما تغلبنا بالتحويلة. ح5: كل شيء كان ميسر. ح6: ما غلبوني في التحويلة.. سهلة. ح7: ما تغلبنا في التحويلة.. ما في مشاكل. ح8: لوما خالي.. هو مدير شرطة.. اي ورقة اي تامين بساعدني فيه وبجيبلي ايّاه.. يعني لوماه كان انا بشحد على الباب.. مش سهل.. ورقة تحويلة بموت لمّا اعملها.. هاي خالي مسافر.. هيني في شهر سبعة وما فيش تحويلة. ح9: معانا تأمين.. ما تغلبنا في التحويلات.. ما في غلبة. ح10: ما تغلّبت في التحويلة.
7	**Patient's Needs for improved QoL**	Treatment plan	Health Provider communication style	C4: They hide it from me… the doctor had told my children. It was by chance that I heard them speaking, they should told me, because hiding the truth is not good. I hope they told me in their language, that would be much-more nicer and better, but hearing	ح1: انه (الطبيب) يهتم بالمريض.. يقعد معه 10 دقايق.. مش يعد عدد مرضى بس. ح2: في البداية ما حكولي.. حكوا لجوزي.. بس انا عرفت من نظرات الدكتور انه معي المرض. ح3: احساسي جوّا بقول اه.. وهم بحكولي لألأ. ح3: اعرفت بالصدفة.. بس انا بكيت قلبي من جوا حاسس انو في اشي.. لازم المريض يدري قبل أهل الدار. ح4: خبّوا عليّ.. الدكتور كان حاكي لاولادي.. اسمعتهم بحكوا صدفة.. لازم حكوا لي.. لانه يخبّوا عليّ مش منيح.. لو حكوا الي بلغتهم بتكون الطف.. احسن.. امّا انا اسمع وهم يحكوا.. هذا

				them speaking by chance, that's really bad, it affected me indeed. C8: I was calling for somebody to check my I.V canula, I mean, the least thing to ask for, he said: I am busy, call someone else, call the doctor; you see; I feel like I am a bad guest at their home.	ح5: قالولي احتمال انها تتحول لأورام. ح7: يعني بيجيه الواحد بالتدريج.. باسلوب هيك.. يفهمو كيف.. حاولوا يخبّوا في الأول.. بس بيّن وعرفت.. الموضوع طويل وشائك.. ما بتقدر تخبّيه. ح8: بنادي غلى حدا ييجي يشوفلي الأبرة.. يعني اقل اشي.. بقول مش فاضي.. خلّي حدا ثاني.. نادي الدكتور.. يعني بحس انهم محمّلينّي جميلة انهم مقعدينّي عندهم.
			Multidisciplinary team availability	C2: Every human, especially the patient, needs for counseling. But I did not find anybody like this in the hospital.	ح1: لازم يكون العلاج كله هون، ما بصير يوديني برّة، لازم يكتبلي تحويلة لطبيب بنفس المستشفى. ح2: كل انسان .. خاصة المريض.. بحتاج لحدا يرشده.. بس ما لقيت حدا هيك. ح4: لو في منيح.. بس ما فيش (دعم نفسي اجتماعي). ح5: اخصائيين نفسي اجتماعي.. لا.. زي هيك ما شفتش.
			Sharing in decision making process		ح8: لكم مرّة بدي اجي.. هاي ثامن ابرة باخذ.. كم مرّة بدي اجي.. طب احكولي الرقم.
			Health education		ح2: بدي كمان معلومات.. مش عارف. ح6: بقروني و سوولي هالكيس.. بعد الكيس نبز النزيف.. انا داري شو هاظ.. الحمد لله.

				C7: Dealing with the disease is ok for me; I do what doctors are saying, I have no experience in such things. But I like everything to be clear for me; I want to know everything about my case and my disease.	ح7: التعامل مع المرض.. عادي.. زي ما يقولوا الدكاترة بمشي.. انا ما عنديش خبرة في هاي الاشياء.. بس بحب يكون كل اشي واضح.. بدي اعرف كل اشي عن حالتي و مرضي.
			Medication, diagnostics & supplies availability	C7: When the medication is not available, we buy it by cash, and moreover, these tests are very expensive, a thousand and a thousand and eight… it should be available; sometimes we were obliged to do them outside.	ح7: الدواء لمّا ما بكون موجود.. شريناه نقدي.. بعدين الفحوصات هاي غالية كثير.. الف شيقل و الف و ثمانية.. لازم يوفروها.. مرات كنّا نعملها برّة. ح9: كنت أتحمّل الوجع.
			Cosmetic prosthetics availability		ح1: احنا منشتريها على حسابنا. ح7: المعدات التجميلية مش متوفرة.
		Economical support	Availability of transportation		ح1: بس لما كنا نطلع في الباص ما نتغلب. ح4: مشوار.. اقرب بكون اريح طبعا. ح8: مهو المشوار عليّ تعب.
			Good housing and house sanitation		ح1: ما في محل خاص اقعد فيه.. لا شمس لا هوا. ح4: دوشة الاولاد كانت تاثر علي.. ما في خصوصية.
			Financial support	C8: The way from Nablus is very far, I need at least a hundred shekels just for transportation, not counting any food or drink.	ح6: القرايب بدعمو بس نفسيا.. مصاري لأ. ح8: مشوار نابلس بعيد كثير.. بدي مئة شيقل هيك.. بدون أكل ولا شرب.

		Psychosocial support	Spiritual & emotional support		ح5: انا بعتقد انه اهم شيء انك تحاول تهدي نفسية المريض.. اول اشي.. انه ما يخاف من هذا المرض.. يعني تعطيه اول اشي انو الاعمار بيد الله.. و انه الألم رحمة من رب العالمين.. بدك تتحمل.. يعني شجعه.. ثاني شيء بده ياخذ علاجه. ح8: بفكرش في المستقبل.. كله على الله.. على التساهيل. ح8: يشوفوني ببكي.. يجيبولي اخصائية اجتماعية.. بس تقولي كيف حالك.. اهم اشي للمريض.. الراحة النفسية.. ولا بحس براحة في اي مستشفى.
			Support group availability	C3: All cancer patients whom I know had died, but only this woman survived. She had talked to me and helped me, she improved my spirits and morale, she had the disease and she is still alive!	ح3: اللي بعرفهم ماتوا.. بس هاي المرأة طابت.. حكت معي ساعدتني.. رفعتلي معنوياتي.. كان معها المرض و بعدها عايشة!
		Care center system management	Better Waiting time management	C8: It is the order in the outpatient clinics down, there is no order; I am usually from 10am till 6pm, also in the other hospital; they thought I am crying because I am angry with my husband or my family… but, I am here since 7am, awaiting till 1pm for the	ح1: في ضغط كبير.. عدد الأطباء و الممرضين مش كافي.. و عدد الأيام كمان. ح8: بس النظام تحت في العيادات.. فش نظام.. باجي من العشرة للستّة.. و في المستشفى الثاني.. بفكروني ببكي زعلانة من من جوزي او اهلي.. بس انا باجي من السبعة.. للوحدة تتطلع نتيجة الفحص.. وانا بستنّى.. ما

				result of the blood test… I ask them, but they say: do you think you are the only one at the hospital… indeed, I am the first one here, even before they start work in the morning… when I do the blood test outside in a lab, it is five minutes, but they do not accept it.	
			Palliative care services	C1: Any patient would be in need for such thing, I wish, it would be of great help. Sometimes, I am not in the mode to step outside the house.	ح1: أي مريض بحاجة لهيك أشي (الرعاية التلطيفية و المنزلية).. يا ريت، كثير بساعد، في اوقات ما بكون الي نفس اطلع من الدار. ح7: لأ.. ما فش مؤسسات تساعد نفسي او اجتماعي او اشي.. يا ريت يكون في اشي زي هيك.. ما في. ح9: انشالله يتوفر هيك مركز.. (رعاية تلطيفية) ممتاز.. بساعد. ح10: مؤسسات داعمة.. والله ما لقيتش.
			Facility and capacity	C8: They took me to Ramallah… they did not have a free bed for me. I wish there is a near treatment center… I wish indeed.	ح7: هم الله يكون بعونهم.. نسبة المرضى كثير كثير.. يدوب يكفّوا.. في عدد كبير. ح8: حمّلوني على رام الله.. معندهمش سرير فاضي.. ياريت لو في مركزعلاج قريب.. يا ريت. ح9: لو الكيماوي موفر في رام الله.. بسهلوا علينا.. عشان ما نيجي على مطرح بعيد.. مش سهل.. بهوّنوا علينا تعب و جهد.

8	**Community perceptions for cancer and cancer patients**	Pity feelings with cancer patient		C1: The way people look to me is painful; they have pity and sympathy with that poor patient. This is too bad, it affects the psychology. Our community does not accept it, they usually say may God heal you and preserve you for your kids… they let you feel it is the end of your life.	ح1: نظرة الناس مؤلمة جدا.. بتصير عندهم نظرة عطف و شفقة.. انه (المريض) مسكين يا حرام، هذا كثير سيء.. بأثر على النفسية.. بالنسبة لمجتمعنا ما بتقبل.. بقولو الله يشفيكي و يخليكي لاولادك.. بحسسوك انه نهاية العمر. ح2: اللي حوليا بكونوا شفقانين عليّ. ح3: بشوفهم بنظروا اله.. شفقة. ح5: نظرة الناس بنظرولك نظرة شفقة. ح7: امن لو كل واحد ييجي يطلّع فيك يعطيك نظرة شفقة.. طبعا هاد بأثر سلبا على الواحد.. انا بحبش نظرة الشفقة هاي.
		Stigmatization of cancer		C1: My mother-in-law wanted to change her daughter-in-law… they say: don't tell her that those like her already died. I don't want people to say it is hereditary disease, this affected my daughters.	ح1: (حماتي) صار بدها تغيّر كنتها.. ما تحكو الها انه اللي زيّها ماتو.. ما يقولو عامل وراثي، هذا أثر على بناتي. ح3: اذا انصبت انا.. بكرة بتنصاب بنتي و اختي.. هذا بأثر.. بتجوزنش مثلا. ح8: سألوا الدكتور.. أهلي و أهل جوزي.. قالوا له.. بعدي؟.. قال لهم.. ما بعدي.. توكل وتشرب معاكوا. ح8: الناس كثير بخافوا.. الكل بقول.. مسكينة.. معاها هذاك المرض.. حتى الأسم ما بحكوه.
		Fatal / serious disease		C4: It is terrifying disease, people perceive it as dangerous… they are usually asking about the cancer	ح4: الو رهبة.. الناس بتطلعوا للمرض انه خطير.. بسألوا كيف فلان.. مات.. لهلحين طيب.

				patient… how is he? Did he die? Is he still alive?	ح5: نظرة الناس بنظرولك نظرة شفقة.. انو هذا الانسان بقضّي بايام.. بس هيك بودّع. ح7: في ناس بخافوا من المرض.. بس هو بعديش. ح8: الناس بقولوا.. الله يساعدك.. الله يشفيكي.. بحس حالي انّي بدي أموت. ح10: بعض الناس بتخاف.. بس الموت بايد ربنا.
		Consider it as punishment		C7: They are not faithful people, they are not believers that this is ordeal and test from God… they say that this person did mistakes so he got cancer.	ح7: هدول ناس مش مؤمنين.. يامنوش بالأبتلاء.. بقولك هاد عمل غلط و صار معه هيك.
		Solidarity and Welling to help		C6: People… they don't help at all… nothing at all. C9: Everybody was kind with me, supporting my spirits, was good to me, compassion and cooperative… thanks God.	ح2: في ناس بساعدوا و في ناس لا. ح6: الناس.. ولا حاجة.. ولا بساعدوا ولا اشي. ح7: المجتمع.. اه.. وفّر دعم.. ساعدني .. اه. ح9: أنا الكل كان متلاطف معاي.. يرفع معنوياتي.. منيح معاي.. حنون و متعاون.. الحمد لله.

Annex (3)

الأستبانة

البيانات الديموغرافية الأحصائية

1) العمر: .....

2) الجنس أ) ذكر ب) أنثى

3) التعليم

أ) لا يقرأ ب) ابتدائي ج) ثانوي د) جامعي

4) السكن أ) مدينة ب) قرية ج) مخيم د) أسم المحافظة .....

5) الدخل الشهري

أ) أقل من 2000 ب) 2000 – 4000 ج) أكثر من 4000

6) الشخص الذي يعتني بك (يمكن الأشارة لأكثر من بند / خيار)

أ) أعتني بنفسي ب) أحد أفراد العائلة ج) شخص مدفوع الأجر

7) الحالة الأجتماعية

أ) أعزب ب) متزوج ج) غير ذلك

8) الظروف المعيشية

أ) اسكن لوحدي ب) مع عائلة ج) غير ذلك، حدد .....

9) نوع السكن

أ) أجار ب) ملك

10)عدد افراد الأسرة الذين يسكنون معك في نفس البيت: .....

11)مكان العلاج

أ) مستشفى بيت جالا ب) مستشفى الوطني ج) مستشفى المطلع د) مستشفى طول كرم

12)قسم العلاج: أ) عيادات خارجية ب) أقسام داخلية

13)مرحلة المرض

أ) I ب) II ج) III د) IV

14)التشخيص .....

15)منذ متى تأخذ \ تأخذين العلاج

أ) أقل من 3 شهر ب) من 3 – 6 أشهر ج) اكثر من 6 أشهر

16)نوع العلاج (يمكن اختيار اكثر من خيار)

أ) كيماوي ب) أشعاع ج) جراحي د) طب بديل\ أعشاب

17)في حال الحاجة الى خدمات أخرى خارج المستشفى، من هي المؤسسات التي تتوجه اليها؟

18)ما هي نوعية الخدمات التي تلقيتها من تلك المؤسسات؟ (في سؤال 15 السابق)

.....

19)ما هي طبيعة المساعدات أو الخدمات التي تحتاج إليها أو ترغب في الحصول عليها؟

.....

EORTC QLQ-C30 (Version 3)

نحن معنيون ببعض المعلومات عنك و عن صحتك لذا الرجاء الإجابة بنفسك عن كل من الأسئلة التالية و ذلك بوضع دائرة حول الإجابة الأكثر ملائمة لك علما بانه لا يوجد جواب "صحيح" أو "خطأ" كما أن جميع المعلومات ستعامل بسرية تامة.

الرجاء إملاء الحروف الأولى من اسم ⌊_⌊_⌊_⌊_⌋

تاريخ ميلادك (اليوم، الشهر، السنة) ⌊_⌊_⌋_⌊_⌊_⌋_⌊_⌊_⌋

تاريخ اليوم (اليوم، الشهر، السنة) ⌊_⌊_⌋_⌊_⌊_⌋_⌊_⌊_⌋

	إطلاقاً	قليلا	بما فيه الكفاية	كثيرا جدا
1. هل لديك صعوبة في بذل مجهود جسدي شاق(متعب) مثل حمل كيس مشتريات ثقيل أو حقيبة؟	1	2	3	4
2. هل لديك صعوبة بالمشي لمسافة طويلة؟	1	2	3	4
3. هل لديك صعوبة بالمشي لمسافة قصيرة خارج البيت؟	1	2	3	4
4. هل تحتاج للبقاء في السرير أو الكرسي خلال اليوم؟	1	2	3	4
5. هل تحتاج للمساعدة في الأكل، ارتداء الملابس، الاغتسال أو استخدام المرحاض؟	1	2	3	4

خلال الأسبوع الماضي تحديداً:

6. هل كنت محدود/ مقيد بالقيام بعملك أو نشاطات يومية أخرى؟	1	2	3	4
7. هل كنت محدود/ مقيد في ممارسة هواياتك او نشاطات في اوقات الفراغ؟	1	2	3	4
8. هل شعرت بضيق بالنفس؟	1	2	3	4
9. هل كان لديك ألم او وجع؟	1	2	3	4
10. هل كنت بحاجة للراحة؟	1	2	3	4
11. هل عانيت من مشاكل بالنوم (الأرق/ صعوبة بالنوم/تقطع النوم)؟	1	2	3	4
12. هل شعرت بالضعف؟	1	2	3	4
13. هل فقدت شهيتك (القدرة على الاكل)؟	1	2	3	4
14. هل شعرت باللغثيان (اللعيان)؟	1	2	3	4
15. هل تقيأت؟	1	2	3	4
16. هل عانيت من إمساك؟	1	2	3	4

انتقل إلى الصفحة التالية من فضلك

خلال الأسبوع الماضي تحديداً:	إطلاقاً	قليلا	بما فيه الكفاية	كثيرا جدا
17. هل كان لديك إسهال؟	1	2	3	4
18. هل كنت متعب؟	1	2	3	4
19. هل الوجع شوش نشاطاتك اليومية؟	1	2	3	4
20. هل كان لديك صعوبة بالتركيز في بعض الأمور مثل قراءة الجريدة أو مشاهدة التلفزيون؟	1	2	3	4
21. هل شعرت بالتوتر؟	1	2	3	4
22. هل شعرت بالقلق؟	1	2	3	4
23. هل شعرت بالهيجان (عصبية/إنزعاج)؟	1	2	3	4
24. هل شعرت بالاكتئاب؟	1	2	3	4
25. هل كانت لديك صعوبة بتذكر الأشياء؟	1	2	3	4
26. هل حالتك الجسدية أو علاجك الطبي أثرا على حياتك العائلية؟	1	2	3	4
27. هل حالتك الجسدية أو علاجك الطبي أثرا على حياتك الاجتماعية؟	1	2	3	4
28. هل حالتك الجسدية أو علاجك الطبي أديا إلى مشاكل مالية؟	1	2	3	4

في الأسئلة التالية الرجاء الإشارة بدائرة حول الأرقام بين 1 - 7 الاكثر ملائمة لك؟

29. كيف تدرج / تدرجي صحتك عموما خلال الأسبوع الماضي؟

1	2	3	4	5	6	7
سيء جدا						ممتاز

30. كيف تدرج / تدرجي جودة حياتك عموما/ مستوى حياتك عموماً خلال الأسبوع الماضي؟

1	2	3	4	5	6	7
سيء جدا						ممتاز

EORTC QLQ-C30 (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials: ⌊_⌋⌊_⌋⌊_⌋⌊_⌋

Your birthdate (Day, Month, Year): ⌊_⌋⌊_⌋⌊_⌋⌊_⌋⌊_⌋⌊_⌋⌊_⌋⌊_⌋

Today's date (Day, Month, Year): 31 ⌊_⌋⌊_⌋⌊_⌋⌊_⌋⌊_⌋⌊_⌋⌊_⌋⌊_⌋

		Not at All	A Little	Quite a Bit	Very Much
1.	Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2.	Do you have any trouble taking a long walk?	1	2	3	4
3.	Do you have any trouble taking a short walk outside of the house?	1	2	3	4
4.	Do you need to stay in bed or a chair during the day?	1	2	3	4
5.	Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

During the past week:

		Not at All	A Little	Quite a Bit	Very Much
6.	Were you limited in doing either your work or other daily activities?	1	2	3	4
7.	Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8.	Were you short of breath?	1	2	3	4
9.	Have you had pain?	1	2	3	4
10.	Did you need to rest?	1	2	3	4
11.	Have you had trouble sleeping?	1	2	3	4
12.	Have you felt weak?	1	2	3	4
13.	Have you lacked appetite?	1	2	3	4
14.	Have you felt nauseated?	1	2	3	4
15.	Have you vomited?	1	2	3	4
16.	Have you been constipated?	1	2	3	4

Please go on to the next page

During the past week:	**Not at All**	**A Little**	**Quite a Bit**	**Very Much**
17. Have you had diarrhea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your family life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your social activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

29. How would you rate your overall health during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

30. How would you rate your overall quality of life during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

Annex (6)

أستبيان الدراسة النوعية: المقابلات المتعمقة **2012**

السؤال الرئيسي	الموضوعات قيد الطرح
1) كيف أثر المرض على حياتك اليومية؟ ما هي تفاعلات المرض مع حياتك اليومية؟	– الظروف المعيشية الحياتية اليومية – عدد افراد الأسرة – الخصوصية في البيت – توفر الخدمات و الامكانيات في البيت/ غرفة خاصة/ حمام خاص – التأثير على الحياة الأسرية العائلية/ الحياة الجنسية o هل قدم الطاقم الصحي نصائح او معلومات حول امكانية ممارسة الجنس؟ – ترتيبات اسرية و معيشية/ رعاية الأطفال – التخطيط للمستقبل/ الحياة و الموت – التأثير على النفسية/ المعنويات
2) كيف تتعامل مع المرض؟	– التعامل مع الألم/ الأعراض الجانبية – تقبل و تفهم المرض/ العوامل المساعدة/ عوامل القوة o وسائل التأقلم مع المرض/ الاستراتيجيات o الدين/ الروحانيات/ الصلاة o التمارين الرياضية/ اليوغا/ التأمل/ الموسيقى o وسائل اخرى/ الطب العربي/ الشعوذة o القيم و المفاهيم المتعلقة بالمرض/ الألم o ما تريد ان تعرفه عن المرض/ يعرفه الأخرون o ما يساعدك على اتخاذ القرار/ روحانيات/ ايمان/ خبرة سابقة شخصية او عائلية o عوامل اجتماعية و ثقافية تؤثر في التجربة/ الجنس/ العائلة/ الدور الأجتماعي/ الضغط/ التوقعات o الانسجام مع الأشخاص الناجين من المرض o امكانية الشفاء من المرض/ مراحله – الأهداف/ الأمال/ التوقعات o المخاوف/ الأهتمامات المتعلقة بالمرض/ بالموت/ بالفقدان – الحاجة للدعم/ العائلة/ الأصدقاء/ الناجيين – ما هو سبب الأصابة بالمرض؟
3) ما هي الترتيبات التي عليك القيام بها للحصول على الرعاية الصحية؟	– ظروف سياسية/ تصريح/ رفض أمني أسرائيلي/ تصريح للمرافق – الأجراءات الادارية في المستشفى/ الوزارة/ تحويلة/ تأمين– عملية طويلة معقدة لاخذ العلاج – الترتيبات المادية/ الأمكانيات المالية – وجود عوائق جغرافية/ امكانية الوصول للخدمة/ المواصلات – وجود مؤسسات داعمة. توفر مرافق للمريض

4) كيف تقيم الخدمات الصحية المقدمة لك؟	– وفرة و جودة العلاج/ الدواء/ الفحوصات o سهولة الحصول على الخدمة – عوامل متعلقة بالطاقم o تعامل الطاقم الطبي o توفر الدعم النفسي o توفر الدعم /الرعاية الأجتماعية – توفر التثقيف الصحي للتعامل مع الأعراض الجانبية – مستوى الراحة في التعامل مع النظام الصحي/ o الثقة بقدرة النظام على التعامل مع المرض – توفر الحاجات و المتطلبات الروحانية عند الطلب o هل كانت لديك احتياجات أو متطلبات لم يتم الأيفاء بها؟
5) ما هي الأمور/ الأشياء التي يجب وجودها لتوفير جودة و نوعية حياة عالية لمريض السرطان؟	– توفر الخدمات الأجتماعية /النفسية – القدرة على التعامل مع الألم و التخلص منه – توفر الدواء اللازم في متناول اليد – توفر المعدات اللازمة لراحة المريض – توفر الطواقم الطبية المتخصصة – وجود الرعاية التلطيفية – توفر المعدات التجميلية/ باروكة – امكانية تواجد الأهل مع المريض – توفر مركز – مستشفى خاص لرعاية المريض – توفر الرعاية المنزلية
6) كيف ترى نظرة الناس/ المجتمع بشكل عام لمرض السرطان في فلسطين؟	– يحرص افراد العائلة و المحيطين على اخفاء خبر المرض قدر المستطاع عن المريض – يراه الناس كوصمة العار/ عيب/ يمنع الزواج/ الأنسجام الأجتماعي – يخافون منه و من التعامل معه/ يعني الموت/ معدي – يرون انه عقاب من الله على الخطايا/ او انه رحمة و ابتلاء – يتقبلون (لا يتقبلون) مساعدة المصاب بالمرض – يوفر المجتمع/ العائلة/ الأفراد الدعم اللازم للمريض

Annex (7): Tool Use Approval

QLQ-C30 download request from Mohamad Khleif

FROM: qlqc30@eortc.be
TO: mkhleif@yahoo.com
Friday, February 10, 2012 8:43 PM
Dear Sir/Madam,

Please find below the links where you can download the documents you requested.

Best regards,

Your data:

Title: Mr.
Firstname: Mohamad
Lastname: Khleif
Hospital/Institution: AL-Quds University
Address: Abo Deis
County/State: Jerusalem
Postal Code: 970
Country: West Bank
Phone: 972 522495249
Fax:
Email: mkhleif@yahoo.com
Protocol: EORTC QLQ-C30

Documents requested:

QLQ-C30 Core Questionnaire in Arabic
QLQ-C30 Core Questionnaire in Arabic
QLQ-C30 Core Questionnaire in English
QLQ-C30 Scoring Manual

URLs:

http://www.eortc.be/home/qol/files/C30/QLQ-C30%20Arabic1.1.(UAE,Egypt,the%20Arabian%20peninsula,Middle%20East).pdf
http://www.eortc.be/home/qol/files/C30/QLQ-C30%20Arabic1.2.(Maghreb-Algeria,Libya,Morocco,Tunisia).pdf
http://www.eortc.be/home/qol/files/C30/QLQ-C30%20English.pdf
http://www.eortc.be/home/qol/files/SCManualQLQ-C30.pdf

If the links don't work, you can copy and paste the entire URL (so with .pdf included)

into your browser and that should work.If you are having other technical difficulties please contact us by email: qlqc30@eortc.be

RE: use of EORTC QLQ 30 for academic research

FROM: Rossella Guzzo
TO: 'moh'd khleif'
Monday, February 13, 2012 1:39 PM

Dear Mohamad Khleif,

Thank you for your request and your interest in our measures.

To obtain a copy of the QLQ-C30 and other validated modules, which are copyrighted instruments, please visit our website, http://groups.eortc.be/qol/questionnaires_downloads.htm where you will be able to fill in a download request.

Once on the web, click the link of the questionnaire you require. A new screen opens where you should fill in your details (You must fill in each area, if you do not have a fax number, please put your tel. number into that area), once you have completed them at the bottom of this page click on SUBMIT. On the next page select the documents you require (questionnaires, languages, full reference values manual, or parts of the manual). At the bottom of the page you need to tick the box that you agree to the terms of the User's agreement. If you have done that, click on SUBMIT and then your request will be sent through. You will automatically receive an email with the download details of the documents you requested. Therefore it is essential that you have filled in your proper email address. So please check it carefully to avoid any inconvenience.

Please feel free to contact me again if you should need anything further.

Kind regards,

Rossella

Rossella Guzzo Foliaro
EORTC, Quality of Life Department Assistant
Tel: +32 2 77416 78
Fax:+32 (0) 2 779 4568
Avenue E. Mounier 83/11 • 1200 Brussels • Belgium
rossella.guzzo@eortc.be
http://groups.eortc.be/qol

50 years of Progress Against Cancer [1962–2012]

From: moh'd khleif [mailto:mkhleif@yahoo.com]
Sent: Friday, 10 February, 2012 19:25
To: Rossella Guzzo
Subject: use of EORTC QLQ 30 for academic research

Dear Sir/ Madam;

I am a master student at AL-Quds University in the faculty of public health. my master will be in health policy and management. I am planning to conduct a research on the quality of life of cancer patients in Palestine. I have found your tool through my reviewing of the literature, and it is already translated to Arabic and used in neighboring countries, including Palestine in one of the small researches done in 2010. I am contacting you for permission to use your tool in my research questionnaire to measure the quality of life of the Palestinian cancer patients.

I hope to hear from you soon. I am ready to provide any needed information about myself or my proposed research.

Very best regards;

Mohamad Khleif

Mohamad H. Khleif RN, BSN, Master candidate
AL-Quds University
Jerusalem

Annex (8)

نموذج موافقة مستنيرة على المشاركة في بحث علمي

انت مدعو للمشاركة في بحث علمي يقوم به احد طلاب الماجستير في جامعة القدس في كلية الصحة العامة في برنامج السياسات و الادارة الصحية. نحن نتطلع الى الافادة العلمية من خلال دراسة نوعية الحياة للمرضى في فلسطين, و ذلك من خلال استكشاف طرق الادارة و التحكم بالالم و الاعراض لدى المرضى. يهدف هذا البحث الى دراسة نوعية و جودة الحياة المرضى, كما يهدف الى تسليط الضوء على اي محددات ثقافية او اجتماعية او سياسية او عقائدية فكرية خاصة لدى المرضى الفلسطينيين. يهدف البحث ايضا الى بيان الحاجة الى توفر برامج الرعاية التلطيفية و التحكم بالالم و الاعراض المصاحبة للمرض ضمن الخطة الصحية العلاجية للمرضى، و مقارنة النتائج محليا و عالميا.

المشاركة في هذا البحث هي اختيارية محضة, حيث تم اختيارك بشكل عشوائي من بين المرضى الاخرين ضمن نفس المواصفات. كما انه لا توجد اي مخاطر جسدية او نفسية متعلقة بالمشاركة, مع ضمان السرية و الخصوصية التامة للمشاركين في هذه الدراسة, مع التعهد بعدم استخدام اي معلومات شخصية او طبية لغير اغراض البحث العلمي فقط, مؤكدين على ان الاسماء غير مطلوبة و تبقى سرية. كما ان المشاركة في هذا البحث تعود بالفائدة عليك و على جميع المرضى من خلال لفت الانتباه الى نوعية حياة المرضى و الحاجات الجسدية و النفسية لهم, و رفع ذلك الى مستوى اخذي القرار في الوطن. مع عدم التعهد باي منافع شخصية مباشرة للمشاركين في البحث.

اذا قررت المشاركة في هذه الدراسة سوف يقوم شخص مهني بمقابلتك و اعطائك استبيان لملئه في مدة لا تتجاوز الربع ساعة, و نؤكد على انه يبقى لك كامل الحق في المشاركة في الدراسة او رفضها او الانسحاب منها في اي وقت تشاء. كما نؤكد ان لجنة خاصة في الجامعة قامت بمراجعة هذا البحث العلمي واعطاء الموافقة عليه ضمن المعايير العلمية و البحثية الوطنية و العالمية المعمول بها في الجامعة.

سوف يتم اعطاؤك نسخة من هذا النموذج لتبقى معك, و في حال وجود اي استفسار حالي او لاحق يمكن الاتصال مع الشخص القائم على البحث في اي وقت على العنوان التالي:

الاسم: محمد خليف

المهنة: طالب ماجستير في كلية الصحة العامة في جامعة القدس \ برنامج السياسات و الأدارة الصحية.

هاتف: 0597594811 بريد الكتروني: mkhleif@yahoo.com

انت في طور الموافقة على المشاركة في هذا البحث, و توقيعك فيما يلي يعني هذه الموافقة و متضمنا اقرارك بقراءة ما تقدم في هذا النموذج.

المشارك: _____ التوقيع: _____

التاريخ: _____

Annex (9)

The Lutheran World Federation
Augusta Victoria Hospital
Est. 1950 - Jerusalem

الإتحاد اللوثري العالمي
مستشفى الأوغستا فكتوريا / المطّلع
تأسس ١٩٥٠ - القدس

15/5/2012

حضرة د. أسمى الإمام المحترمة
كلية الصحة العامة
جامعة القدس

الموضوع: مساعدة الطالب محمد خلف

تحية طيبة وبعد،

بالإشارة إلى كتابكم الوارد إلينا بتاريخ 2012/5/8، والذي ينصّ على تسهيل مهمة الطالب محمد خلف في عمل أُطروحة الماجستير، فإننا نود أن نخبركم بأنه لا مانع لدينا، وذلك بعد إرسال نسخة من الاستبيان ليتسنى الإطلاع على فحوى الأسئلة.

مع الشكر

ملاحظة: يمكن مراسلتنا على البريد الالكتروني arimawi@avh.org

عاطف الريماوي
المدير الإداري
ومدير الموارد البشرية

ATEF AL RIMAWI
Director of Administration
& Human Resources
المدير الإداري ومدير الموارد البشرية
Augusta Victoria Hospital
Tel 02-6279919

Palestinian National Authority
Ministry of Health - Nablus
General Directorate of Higher &
Continuing Education

السلطة الوطنية الفلسطينية
وزارة الصحة- نابلس
الإدارة العامة للتعليم الصحي

Ref.: .....
Date:.....

الرقم: ٢٠١٢/٧٤٣/١٦٣
التاريخ: ٢٠١٢/٥/٢٨

الأخ مدير عام الإدارة العامة للمستشفيات المحترم ،،،

تحية واحترام،،،

الموضوع: تسهيل مهمة

تماشياً مع سياسة وزارة الصحة المتعلقة بتعزيز التعاون مع الجامعات والمؤسسات الأكاديمية بإتاحة فرص التدريب أمام الطلبة والخريجين والباحثين في المؤسسات الوطنية وإسهاماً في تنمية قدراتهم.

يرجى تسهيل مهمة **طالب ماجستير السياسات والادارة الصحية محمد خليف/ كلية الصحة العامة/ جامعة القدس** بتوزيع استبانه دراسة وعمل مقابلات مع مرضى السرطان في مستشفيات (بيت جالا، الوطني، طولكرم) لعمل بحث كمتطلب لرسالة الماجستير بعنوان "**جودة حياة مرضى السرطان في فلسطين**".

- شريطة موافاتنا بنسخة من النتائج عند اتمام البحث

مع الاحترام،،،

الدكتور سعيد الهموز
مدير عام التعليم الصحي

/ نسخة عميدة كلية الصحة العامة المحترمة/ جامعة القدس

P.O .Box: 14
Tel.:09-2384771 - 6 Fax: 09-2384777
E-mail: pnamoh@palnet.com
ص.ب. 14
تلفون: 09-2384771-6 فاكس: 09-2384777

Annex 11: Expert reviewers of the study tool

The study tool had been reviewed by the following experts:

- Dr. Mohamad Bushnaq, MD, Palliative Care specialist in Jordan. Previously was the head of oncology and palliative care department at King Hussein Cancer Center (KHCC).
- Dr. Foad Sabatein, MD, Oncologist at Beit Jala Hospital in Palestine. Previously was the head of the oncology department at Augusta Victoria Hospital in Jerusalem.
- Dr. Motasem Hamdan, PhD, researcher and Dean of Public Health faculty at AL-Quds University in Palestine.
- Mrs. Amal Dweib Khleif, palliative care nurse specialist in Palestine. Founder and chair of AL-Sadeel Society for Palliative Care for Cancer and Chronic Diseases. Previously was the head nurse of the oncology unit at Augusta Victoria Hospital in Jerusalem.
- Mrs. Niveen Abdel Hadi, social worker in the field of cancer care, works with Palestine Children's Relief Fund (PCRF) in Palestine.